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July 13-15, 1987

National Center for Health Statistics
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DATA FOR AN AGING POPULATION

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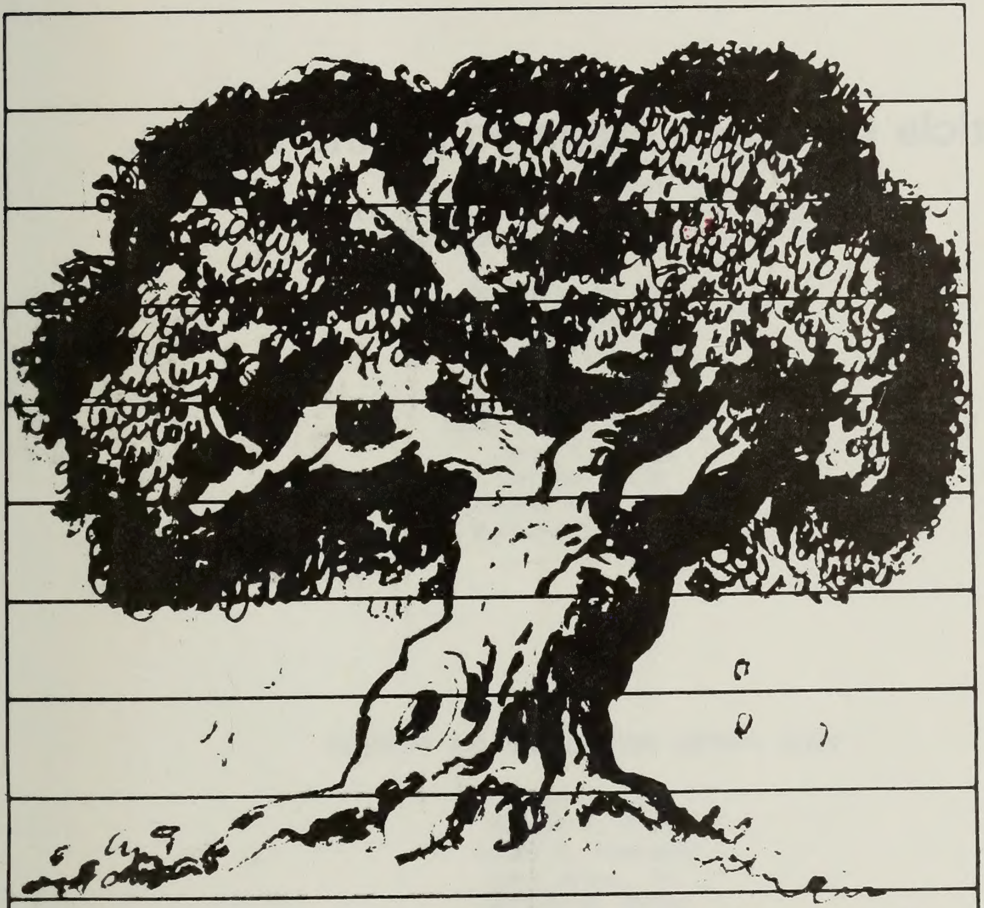

DATA FOR AN AGING POPULATION

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Public Health Service
Centers for Disease Control
National Center for Health Statistics

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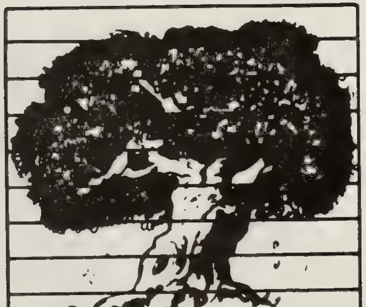
First Plenary Session

Welcome Session

Methodology and Measurement Issues



DATA FOR AN AGING POPULATION

WELCOME SESSION
INTRODUCTORY REMARKS

Manning Feinleib, M.D., Dr.P.H.
Director
National Center for Health Statistics

It is a distinct pleasure to welcome all of you to the 21st Public Health Conference on Records and Statistics. The theme of this conference is Data for an Aging Population, so it is appropriate that the National Center for Health Statistics is joined by two other agencies as co-sponsors: the National Institute on Aging and the Bureau of the Census. You will hear from the Directors from both agencies in a few moments.

The focus of this Conference on Data for An Aging Population is highly relevant to our future as a Nation. We are witnessing the "graying" of America. Today one in every eight Americans is age 65 or older. By the year 2025, this figure will be one in every five Americans. This demographic shift is unprecedented in our history and that of other industrialized Nations as well. At the turn of the last century, life expectancy was 47 years. It has jumped to 75 years today--an addition on the average of 28 years. The oldest-old--those aged 85 and over--are the segment of this group that is growing most rapidly. By 2025, the oldest-old will increase by nearly 400 percent. These dramatic increases forecast changes that will reshape American society and affect each and every one of us. We can expect major changes in health status, in health care use and in health costs. A crucial issue is raised by the 28-year increase in average life expectancy. Are the additional years toward the end of the life span ones where the quality of life is high? Or are they years of major disability and greater dependence on health care? The limited data now available to address this question emphasize the great diversity inherent in America's older population. A majority are living productive lives, free of major chronic disability. A distinct minority, however, has significant chronic disabilities, makes major use of long term care and has high health care bills. As would be expected, the older persons at greatest risk of significant disability are those aged 85 and over--the subgroup which will have the most phenomenal growth in the next 40 years. What changes in this situation will the future bring? Will the impact of chronic conditions be reduced and the proportion of older Americans with disabilities decreased? Those are the key questions.

This Conference was developed to address issues about data on aging in order to contribute to our knowledge base. In a variety of ways, it addresses the issue of what data are needed so we as a Nation can plan for the health needs of an aging society. Data enhance our ability to plan for the future and, in some cases, to influence its course. In my view, data are important to decision making on an individual basis as well as at national, state and local levels. The Conference provides a forum to share experiences and insights. This gathering includes data producers and data users from Federal, State and local governments as well as from universities, professional associations and private organizations. The diversity of such a forum is important. It provides a wealth of perspectives and experiences which can enhance the quality and availability of health data about our aging population.

The Conference has been structured around the topics of health, research and public policy. It has three underlying themes:

- measurement and methodology issues
- public policy issues
- and substantive issues raised by analyses, trends, and projections derived from existing data.

Each theme is highlighted by a morning plenary session. Today's plenary session, for example, concentrates on measurement and methodology issues. These themes also resurface in the concurrent sessions throughout the Conference. I believe you will find the sessions interesting and informative. I would like to thank Joan Van Nostrand, Chair of the Program Planning Committee, and all the Committee members for arranging such a superb program.

We are fortunate to have many foreign guests joining us at this Conference. I have been given the names of some of them. I would like to welcome them. The World Health Organization has sent several representatives. They are David MacFadyen, Edward Dowd, Evegnei Chigan, and Auliki Nissinen. Attending from Israel are Michael Davies, Baruch Modan, and John Goldsmith. Attending from Switzerland are Theodor Abelin and Andreas Stuck. Also attending are Emily Grundy from Kings College, London; Erik Holst from the University of Copenhagen, Denmark; and Nobuo Maeda from the Institute of Public Health, Tokyo, Japan. I know that your contributions will enrich the deliberations and give us different perspectives on how to assemble and use data on the aging population.

As Director of the National Center for Health Statistics, I am aware of the variety of NCHS activities concerning data on the aging which will surface during the conference. Recently, NCHS has increased its efforts in the collection, analysis, and dissemination of health data for an aging society. While I will be discussing these activities in detail in tomorrow's session entitled An Afternoon With

Conference Sponsors, there are several activities which merit special attention.

One activity is the collection of longitudinal data such as in the NHANES I Epidemiologic Followback Study and in the Longitudinal Study on Aging. Data from such longitudinal surveys are needed to study risk factors for disability and death and to ascertain the probability of the use of long-term care. A second activity is filling a major data gap by conducting the National Nursing Home Survey after an 8-year hiatus and by surveying health and service use in the last year of life in the National Mortality Followback Survey. A third activity is evaluating the utility of existing data systems for health policy analysis for an aging society. NCHS joined with several other agencies to fund a project by the National Academy of Sciences to identify critical data needs. That project is nearing completion and a session on it is scheduled for tomorrow afternoon. A fourth activity is that of dissemination. With funding from the National Institute on Aging, NCHS has published the report, Health Statistics of Older Persons. You received a copy at registration. The central feature of the report is that it compiles statistics from all data systems maintained by the Center and presents the information in great detail by age, usually with a separate category for age 85 and over. The fifth activity is the increased emphasis on data for older persons in the upcoming National Health and Nutrition Examination Survey III. If all goes according to plan, there will be no upper age limit and the survey will include persons over the age of 74 for the first time. It will include a series of measurements specifically designed for older persons and the option of an examination in the person's own home. The survey will be an important resource for examining comorbidity and nutrition issues. The next activity is the implementation of an international collaborative effort on selected topics of measuring the health and health care of the aging. This effort includes international collaboration on various projects useful to NCHS and other data users. I will be chairing a session tomorrow morning on international activities in aging. The final activity I would like to mention this morning is in the area of coordination and communication. The NCHS, along with the National Institute on Aging and the Bureau of the Census, is co-chairing the Forum on Aging-Related Statistics. This is an interdepartmental group which meets several times a year to facilitate communication among agencies which collect and analyze data on the aging population. This interaction will enhance coordination and utility of data on aging.

In conclusion, these activities and others you will hear about during this Conference are important to enhance data about the health of an aging population. I know they will strengthen our knowledge base to meet the challenges of an aging society, challenges which this phenomenon presents to all of us as individuals and as a Nation.

WELCOMING REMARKS

T. Franklin Williams, National Institute on Aging

I am certainly privileged to have the opportunity to join my colleagues here in welcoming all of you to this conference and to assure you of the deep and extensive interest of our Institute in this whole topic, "Data for an Aging Population," as well as the opportunities we have to share with our colleagues here in the Federal Government. We certainly are eager to work closely with people throughout the United States and in other countries to make further advances in our understanding of these issues.

Dr. Feinleib and Dr. Windom have already touched on a number of issues that I had considered referring to in my remarks, so I will not repeat them, but let me just try to add a few things about emphases that it seems to me--and my colleagues on our staff--we need to consider in looking at these issues that we are all going to be discussing here.

We have identified a number of gaps in the Federal data systems and in all of our research data bases concerning aging populations and a number of opportunities for further advances in these areas. Some of this again will partly recapitulate points that Dr. Feinleib has already made, but let me list them in the order that I see them as having urgency.

One is the issue of the oldest old population, those aged 85 and older, the fastest growing group in our country, as already referred to. In this area, unfortunately, up to now, many of our national surveys have stopped at age 75 or even earlier at times and, furthermore, have lumped data in the older age groups all into one category.

I might just point out that, even in the Health Statistics for Older Persons report that Dr. Havlik and others have so fortunately prepared to be available by the time of this conference, we are still dealing with a lumping of people age 85 and over, and already it is time for us to begin to look at the breakdowns beyond that--90, 95, 100, as Dr. Windom referred to.

Also there is the fact that the projections out beyond age 100, out into the next century, are very vague about how many people we will have. The projections I have been given are that, by the year 2080, when everybody who will be 100 years old is already born now, the projections are anywhere from 500,000 to 5 million people aged 100 and over. That is a rather wide range of uncertainty and just illustrates some of our needs for better data, especially now and in the future in older people. So the oldest old is a very important category: How do we go further in getting better data and in analyzing it?

Secondly, we clearly need more longitudinal studies. This is one emphasis that our own Institute has made in our own intramural program and in funding other studies. But we need more information about the course of life and particularly the illnesses and other social and economic factors that enter into the course of life in later years as determinants of health or diasability, enjoyment or discomfort.

We need more details in many ways in our data. For example, we need to look more carefully at the transitions of individuals in and out of dependency. We have made a point of emphasizing the view of active life expectancy; what period of life can a person expect to live with good function, not dependent on anyone else to any significant degree. That is a very important datum from the point of view of enjoyment of life but also from the point of view of the burdens of care that do fall on other people when a person passes from an active life into a more dependent status.

We also have to recognize that people make transitions both ways. The more detailed our information, the more we see people returning to an independent role, so that there are many issues around the concept of active life expectancy and the transitions in and out of dependency that need more basic information.

We also need more adequate analysis of the many data that we actually already have. We need more trained scientists in this field, and an important priority is the training of academic and qualified people to deal with the data we are collecting or to help us in our leadership into the future in this field.

In addition to the people, we need to address such issues as timely release of data, making public data tapes on all of the data we collect. Whether collected through intramural routes or extramural routes, federally funded data, in my view, should become available to the entire scientific public as rapidly as possible. As you probably know, our Institute does support the National Archives on Aging-Related Data at the University of Michigan, where we make every effort to get public tapes stored as rapidly as possible and available for further analysis.

There are many opportunities for piggybacking of analyses and carrying out secondary analyses at relatively little expense once the basic data have already been collected and archived in one place or another. Thus there are many challenges in these areas for using more adequately the many data resources we are already achieving.

I want to make a few other comments about the Federal Forum on Aging-related Statistics that was referred to by Dr. Feinleib. In my view, this has been a very satisfying development between the National Center for Health Statistics, the Bureau of the Census, and our National Institute on Aging, where we pull together to try to address the issues about Federal data related to aging, and we have organized the Federal Forum on Aging-related Statistics which has participation from approximately 30 Federal agencies working together to achieve more sharing and more common goals and identifying even further the data gaps that need attention.

We have set up three committees under this Forum, one on data gaps, another on dissemination of data, and another on methodologies. You can see the themes are quite similar to themes that are established for this conference.

I want to thank, particularly, Richard Suzman of our staff, Cynthia Taeuber of the Bureau of the Census, and Joan Van Nostrand of the National Center for Health Statistics, as well as many others who are helping to make this Forum work, and of course we are pleased that we have a special budgetary item this year to help provide for this work.

Beyond these efforts, we see many opportunities to use and apply funds from our Institute through our companion agencies in modest ways to obtain further analyses of data that we can all use. An example is the publication of the "America's Centenarians" report which was available in time for our Centenarians' Day on July 1.

Another example is the International Data Base on Aging in which funds from our Institute--and I believe, in the future, also funds from the Agency for International Development--will help to obtain a more complete international data base, working with the Bureau of the Census.

We see many opportunities for working together across our various agencies and working with our colleagues out in the community.

I would like to close by recounting the quotable quote of one of the 17 vibrant people, all aged 100 and over, who took part in our Centenarians' Day on Capitol Hill. She said that she wanted to remind people that she went out every day because, if death called, she didn't want to be home.

CONVENING OBSERVATIONS

John G. Keane, U.S. Bureau of the Census

At this important conference and to this important audience, I feel impelled to discuss two things this morning: first, purposes and advantages associated with the cooperation of getting a group like this together; and, secondly, an overview of Census Bureau work that is pertinent to the discussion. Then I will have some final sentiments.

In that order, I will first address the purposes and advantages of cooperative action for aging-related statistics. Just think about some of the many purposes and advantages that we have:

- create forums: a forum for problem detection, discussion and resolution; a forum for developing research in data collection techniques; a forum for technology exploration and transfer; plus a forum for linking research to planning and policy.
- set joint priorities in the development of aging-related statistics for the Nation and perhaps the world, that meet the tests of scientific value, social relevance, and affordability, in addition to political visibility and viability.
- encourage collaborative research as well as information and technology sharing among agencies.
- expand our collective ability to link data collection and research to planning and policy development.
- improve access, analysis, dissemination and use of data through coordinated approaches.
- strengthen the collective likelihood of identifying gaps in aging-related statistics in the Federal statistical system.
- extend the use of limited resources among agencies, always a constraint.
- begin to build a bridge between health and socioeconomic data, and eventually between policies in those respective areas.
- and, finally, diligently to develop our networks. The first part is to develop the network process through conferences such as this. That in turn leads to wider networks--the results of which are: contacts, shared interests across agencies, across disciplines, across functions, across races, and ethnic groups, across, Nations -- we just heard about the international flavor here with public health institutes, the World Health Organization, interested professors-and we know about that within the Census Bureau because we have been involved in international work formally for 41 years. And, finally to network across time.

Currently, our work consists of the following:

- Census Bureau-sponsored conference: our Population Division's special office of aging-related statistics is sponsoring a session at the 1987 Public Health Conference on Records and Statistics on the Black aged. The staff will present papers at this conference.
- Census Bureau Publications:
  - You heard that we just published "America's Centenarian Population: Data from the 1980 Census." (Previous speakers mentioned this.)
  - Another publication is a presentation at the 1986 Annual Meeting of the Population Association America. That paper focused on the same topic but from a slightly different angle. The topic is the quality of centenarian data in the 1980 census.
  - A report on income, health, and wealth of the Black aged uses data from the Survey of Income and Program Participation.
  - Another report will provide a demographic portrait of America's oldest old. This is to be done by Cynthia Taeuber and Ira Rosenwaike at the University of Pennsylvania, and is to be published as a book chapter.
  - Another is "Quality of Data on the Older Population in the 1980 Census" by Arnold Goldstein of the Census Bureau. This is due out late this year.
  - "Aging America, 1986," will be the first of what is expected to be an annual report of the most important demographic, social, and economic data produced by the Census Bureau on the older population.
  - And, finally, "An Aging World" by Barbara Torrey, Kevin Kinsella,

and Cynthia Taeuber. This represents, at the Census Bureau, a collaboration of the domestic and the international areas of our institution. This, like the others, is due out before the end of the year.

- One more item is a telephone contact list. This is scheduled to be printed this summer. A telephone contact list might not sound like much, but it, too, is part of the network. It goes to the journalists, and look what they can do to publicize this cause. It goes to congressional members and staffs. It goes to Federal, state, and local governments, plus a host of other diverse users. I see some strategic benefits in this. I do not see this as a perfunctory put-out-a-list-with-names-on-it task that has no life and makes no contribution. The strategic benefits I see from this are education; and closely connected to that, the development of sensitivity for the topic; the uniformity of understanding that can go along with getting the same figures; and finally, helping us to be more anticipatory, which in itself is a laudable goal and achievement.

My final sentiments run along these lines: the Census Bureau is gratified to co-sponsor this conference with the National Center for Health Statictics and the National Institute on Aging. This represents solid evidence of our continuing collaboration.

Also, a low bow to all of those making this conference the success it will surely be, the program and exhibit committees, those planning and handling the logistics behind the scenes, the speakers and the participants and all those who don't fall in any of the previous three categories. Last week, we noted the arrival of the five billionth person in the world. That is a quantity dimension. This week, and in this conference, we focus on the aging of that global population. This is a quality dimension.

So I wish us well in our work so that we may help the world to age as graciously and self renewingly as the place where we meet, the Mayflower Hotel. Perhaps then the graying of our Nation and our world may truly be a golden experience.

WELCOMING REMARKS

George E. Hardy, Jr., Centers for Disease Control

Thank you, Dr. Feinleib. As you have already heard, I have not been asked to speak about aging but I would be remiss if I failed to note that I was the only speaker who required a historical introduction. I did spend the weekend--those of you who were here in Washington can question my sanity--but I did spend the weekend removing brush and weeding and doing some planting that just had to be done, and my back is telling me this morning that I am becoming an expert on aging. But, be that as it may, I have been asked to speak on new relationships. As Dr. Feinleib has just told you, the NCHS and CDC formally joined forces in June of this year. I think most of us are accustomed to dealing with our own inertia and perhaps discomfort when it comes to reorganization and change, so what I would like to do with the two minutes that have been allotted to me this morning is talk a little bit about what these relationships will mean, particularly what these new associations mean for NCHS, for CDC, and for each of you. First, for NCHS, as Dr. Feinleib has already indicated, the National Center will be a separate center within the Centers for Disease Control, and it will retain its ability to work with all of its constituent groups, state and local health departments, all of the Public Health Service agencies, the Health Care Financing Administration, and each of you as it has in the past. For CDC, it means a great deal. I think it means an even stronger partnership between our staff and NCHS in a variety of activities where we have traditionally worked together, areas such as disease surveillance, morbidity and mortality reporting, data analysis, and the opportunity to expand into whole new worlds of joint effort in such diverse areas as occupational and environmental health and, beginning even last week, AIDS. For you, I hope you will notice absolutely no difference at all in the positive relationships you have enjoyed with NCHS over the years, except that I hope, through meetings such as these, we at CDC will become more familiar with you, and you with us, and in time even more extensive and imaginative efforts for collaborative work will develop among us all. The rapid collection and dissemination and transfer of information about the nation's health is probably our most important tool in preventing disease and disability and in promoting health. We recognize NCHS as a major resource in our continuing efforts to provide accurate and current information to our traditional partners in state and local health departments and in all fields of health endeavor. So, as part of CDC, NCHS will continue its national leadership role in vital and health statistics and its close working relationships with all of you. As Dr. Jim Mason, the director of CDC, said when he met with NCHS staff a few weeks ago, "We are proud of the accomplishments--your accomplishments--as national leaders in vital and health statistics, and we welcome you to CDC. We look forward to a strong partnership that will enhance the mission of both of our organizations." I would add to that only that we also would welcome any comments and suggestions from any of you on ways that we can enhance our mutual relationships to improve all our productivity. I want to thank you for inviting me to be part of this meeting, as part of NCHS's expanded family, and to wish you the very best success with your meeting. Thank you very much.

WELCOMING REMARKS

Robert E. Windom, M.D.
Assistant Secretary for Health
Department of Health and Human Services

Thank you, Dr. Feinleib. I appreciate the opportunity to be here with you to open this Conference on behalf of the Department of Health and Human Services. The dramatic increase in the number of older Americans described here today is having profound social, economic and medical consequences. Two weeks ago, I had the opportunity to participate in Centenarians Day where we honored a number of individuals of 100 years of age in the surrounding Washington area. In fact, in many State capitals, governors and legislators and others were doing the same thing to show our respect for those individuals who are living to age 100 or older today. I was struck by how remarkable it is to be living in an era when the over-100 age group is one of the fastest growing segments of the U.S. population.

I think it was appropriate that we celebrated and honored these individuals this year because I am sure each one of you knows that this is the 100th birthday of the National Institutes of Health. One hundred years ago, in a small, one-room laboratory in Staten Island began what today we know as the over $6 billion budget that makes up the National Institutes of Health. So it was appropriate, I think, to look at individuals born that same year who are living today, quite vibrant, quite lively and alert, as they assembled and joined in that celebration with us.

In 1985, the data show that there are over 25,000 centenarians in our nation. By 1990, that will double to 50,000. By the year 2000, it will quadruple to an estimated 100,000 over 100 years of age.

By the year 2030, about 64 million Americans will be age 65 or older. To put that in perspective, that is today's total combined population of California, Florida, New York, and Texas. It is important to focus our attention on this geriatric revolution. It is reshaping American society. Shifts will occur not only in health care, but also in retirement, in housing and in living arrangements. These fundamental shifts will have consequences for every one of us, as well as for the private sector and for local, State, and Federal governments.

We can use data to strengthen our ability to address emerging issues about the aging of our society. These issues focus on health and productivity, the family, and the interface of the public and the private sectors. From the results of research, we have a fuller understanding of the difference between the inevitable results of biological aging and the effects of illness. As Dr. Feinleib noted, life expectancy has increased by 28 years since 1900. Persons reaching the age of 65 now have, on the average, 17 years of life remaining. I know that many will certainly exceed that and go to that centenarian age.

This increase raises a crucial question: How can we assure that these additional years are healthy, productive ones? Our expectations about our increasing life span are becoming more and more positive. For example, we now look to the years after age 65 as a time of vitality, productivity, and continued personal growth.

Before coming to Washington as Assistant Secretary for Health, I had practiced for 26 years in the private sector of internal medicine. While doing that, I had a first-hand opportunity to spend time with many of the wonderful older people who played a great part in the shaping of our nation as it is today. One of the major concerns that I saw and heard them express is the impact of catastrophic health expenditures. I am encouraged that the Department's efforts, as lead by the Secretary Dr. Otis Bowen, in developing recommendations to the President on health care expenditures for catastrophic illness resulted in legislative action on Capital Hill.

The focus of this Conference on Data on Aging is to increase our ability to address America's geriatric revolution. The data presented at these sessions are important to strengthen our knowledge about the health and quality of life of older citizens. The Conference will enhance our ability to meet the ultimate goal: assuring that as Americans age, they remain healthy, productive persons.

As your Assistant Secretary for Health, I want to welcome you, wish you well as you deliberate the next couple of days. I am certain that the results of your input, your expertise, and your knowledge in this area will play an important part in the years to come to meet and accept responsibilities that we all have to those who will continue to live many years longer in this great nation.

NORMAL HUMAN AGING

Richard W. Besdine, University of Conn. Health Center

Biological aging is the inevitable and irreversible price we pay for the remarkable gains in life expectancy recorded world-wide, and particularly in the United States, during the 20th century. Separating the truly irreversible and inevitable biological events from the disease, environmental or life-style effects which are usually confused with normal human aging is the task which has been undertaken with increasing vigor, scope and success during the past three decades; especially in American loci of research productivity. As we have learned more and more about the usual consequences of aging in human tissues and organ systems, and as these studies have been performed in increasingly healthy older persons, a remarkable phenomenon has emerged. Many of the hard-won "facts" about decremental change in organ function as a consequence of aging are being refuted; and a concept of vigorous rather than ordinary aging is emerging.

Although aging is a universal phenomenon which affects every one of us in profound ways, the study of aging has not been a part of mainstream biological research. Most textbooks of biology or medicine make no mention of the subject, yet aging is intrinsic to all higher animals; and its inevitability and universality demand attention. The word "aging" evokes an array of changes based on personal experiences and observations of others. Aging may be considered an inevitable and irreversible process that begins or accelerates at maturity and results in an increasing number of deviations from the ideal of youthful normality.

Demographics

Aging is inevitable and every living organism has a finite life span. Moreover, each species has a characteristic maximum attainable life span. Improved nutrition and health care have increased the average human life expectancy (at birth) from less than 20 years in ancient Greece to well over 70 years in the United States today, but they have not altered the approximately 110 year maximum life span of our species. Like Europe before us, and developing nations in the future, in the United States the elderly population is increasing. Many factors have collaborated over the past century to "age" our society. Understanding the graying of America provides the clinician with an important perspective. The longest-living humans live no longer today than they did centuries ago. Maximum human life span (approximately 110 years) has not changed, but average life expectancy has increased dramatically. Previously unimagined numbers of people are surviving into extreme old age, many with burdens of disease, social disadvantage, emotional vulnerability, and the poverty such burdens create. Average life expectancy in America has increased by more than 25 years during the 20th century, from 47 years in 1900 to 73 years in 1980. For each four months elapsed since 1900, the average American has gained more than one month of life. In 1900 fewer than 3 million people were 65 years of age or older, only 4% of the population. Now, in less than a century, the more than 28 million elderly individuals comprise nearly 12% of our population. Because all individuals who will become 65 years of age and older in the next 50 years have already been born, demographic projections about aging are relatively secure. By the year 2030, the elderly population will double, reaching more than 60 million individuals. If during this period the total U.S. population grows at the projected 40%, more than one in five citizens will be over 65 years of age. The "old-old" (over the age of 75) subset of elderly will increase even faster. Americans older than 75 years of age will increase from 35% of the over 65 population to 45%, and those 85 years of age and older will more than triple from 2.5 million to 8 million individuals.

The increase in the aged U.S. population has been attributed to several phenomena by the lay press. One popular myth contends that large numbers of very elderly Americans survive through the application of new medical technology, which might better be withheld. In fact, death rates for elderly persons have been declining since the end of World War II and are responsible for much of the longevity in our society. More recently, rates of death among very elderly Americans have declined sharply, with dramatic dips in cardiovascular and stroke deaths among the oldest old. Furthermore, most "medical care" longevity emanates not from costly heroic interventions, but rather from salutory life style and diet changes, and from mass detection and treatment programs for hypertension beginning during the 1950s and 1960s.

One historically important component of increased average life expectancy originates at the beginning of life via a dramatic increase in infant survival. Better nutrition and medical care of pregnant women and improved delivery techniques have enhanced the chance for survival of live births. Better sanitation, an improved standard of living, better nutrition, prevention and treatment of infectious diseases, and progress in medical care have all sharply increased the survival rate for children born in America. Much of the life prolonging impact of improved infant survival occurred between 1900 and 1950. Once these children "saved" reach adulthood, they are very likely to survive to old age. In spite of decline in infant mortality, the United States is not among the world leaders in this category; and thus life expectancy at birth is greatest in Japan. But life expectancy in adulthood is greatest in America.

The Physiology of Normal Aging

A thorough understanding of age-related physiologic changes occurring in humans, in the absence of disease, is critical to diagnosis and management of disease in older persons. These physiologic changes influence the presentation of disease, response to treatment, and complications that may develop. Cross-sectional and longitudinal studies in carefully screened community-dwelling persons across the adult age range indicate that increasing age is accompanied by inevitable physiologic changes that are separate from the effects of disease. Growth and development, characterized by rapid increases in many physiologic functions, generally continue into early adulthood, peaking in the late-20's or early-30's. Those functions that change with age after maturity, and not all do, usually show linear decline beginning about age 30 and continuing without change in rate into extremes of aging. Thus, an 80 year-old is aging just as fast as a 30-year-old. The 80-year-old is more aged than the younger counterpart, having accumulated more age-related changes; but loss of function is not occurring more quickly. There is generally no pleasant plateau in mid-life during which physiologic function is stable, but rather there is a progressive age-related reduction in the function of many organs.

Variability is an important characteristic of age-related changes, both within individuals from organ to organ, and from individual to individual in a given population. Such functions as glomerular filtration rate and carbohydrate tolerance change rather dramatically; whereas others, such as fasting blood sugar and hematocrit, undergo little change into the eighth or ninth decade.

Changes in one organ do not predict or correlate with those in other organs. A healthy 70 year-old whose renal function on serial prospective measurements is falling at a certain specific rate, perhaps at the rate average for his age group, must be studied to learn of any trends in other organs. Information about the kidney is of no value in predicting the rate at which heart, lungs, bladder, or any other organ is changing with time. The lack of synchrony among organs in their age-related changes appears to rule against a basic biologic clock. The variability and unpredictability of biologic aging in an individual has thus far defeated the search for a predictor of physiologic or psychologic performance better than chronological age.

As noted, there is also substantial variability in human aging from individual to individual. Functions that change in major ways with age exhibit large variance, and one can easily identify healthy 80-year-olds with organ function at the same level as the average 40-year-old, and vice versa.

Ordinary versus vigorous normal aging

As noted above, there is substantial variability in the magnitude of age-related physiologic changes. The older individuals become, the less like each other physiologically they become; perhaps, in part, due to lifestyle differences which comingle with the effects of aging. Although maximal oxygen consumption (VO_2 max) has repeatedly been shown to decline with age, for example, studies also demonstrate increased oxygen consumption after exercise training in older persons. Older athletes achieve a VO_2 max higher than in average young adults, but not as high as in young, equally conditioned athletes. As increasing attention is paid to the potential beneficial effects of exercise, diet, avoiding smoking and moderation in alcohol intake, it is likely that increasing numbers of vigorous older persons will be identified who demonstrate vigorous aging. Not only are they free of disease, but also they perform physiologically only modestly lower than healthy young adults. This optimism aside, most older adults currently exhibit ordinary normal aging. Here we see aging-related decrements exaggerated by negative effects of confounding environmental, dietary, genetic or lifestyle factors. Most studies in the literature on the physiology of aging, although they exclude diseased older individuals, describe ordinary rather than vigorous aging.

Distinction between aging and disease

When illness is superimposed on

age-related changes, the classic parallel lines of normal human biology and disease converge at the elderly patient, causing a dilemma for the clinician unschooled in gerontology and geriatric medicine. Here also a substantial new knowledge base concerning differences in clinical phenomena in the elderly, largely attributable to the altered substrate produced by the impact of normal aging, has appeared. The need for detailed elucidation of normal biologic aging and its influence on disease is obvious when we consider the potential for confusion of the practitioner encountering a sick old person. This patient has biobehavioral and functional abnormalities not found in younger healthy individuals, but whether the observed differences are attributable to aging or disease cannot be ascertained without a detailed understanding of the multiple changes resulting from normal human aging. Only with a clear view of normative age-related changes can the physician properly evaluate and treat a sick old person. Ignorance of these data has two equally dangerous consequences. First, normal, age-related changes may be attributed to disease, provoking treatment that will certainly be ineffective and will likely do harm. Alternatively, disease effects are mistakenly attributed to normal aging and neglected, allowing unchecked progression of a potentially treatable underlying disease. A third outcome, and perhaps the most destructive, is the avoidance of elderly patients altogether by clinicians frustrated and discouraged by unsuccessful interactions with aged individuals whose multiple problems have disease and age-related components. Accordingly, we will systematically review here the interplay between normal aging and disease to inform or remind clinicians of the unusual or unique aspects of providing health care to older persons.

Specific physiologic functions and aging

Linear decline of organ function is a common phenomenon in healthy older persons. These declines occur in the following functions:

1. Elastic recoil of the lung
2. Arterial partial pressure of oxygen
3. Vital capacity of the lung
4. Maximum breathing capacity
5. Quantity of B-cell mediated specific immunoglobin production
6. Helper T-cell numbers and their functions
7. Lean body mass
8. Total body water
9. Dopaminergic function in substantia nigra
10. Ability to prevent postural sway
11. Ability to prevent orthostatic hypotension
12. Renal blood flow and creatinine clearance
13. Renal ability to conserve sodium
14. Renal ability to excrete water
15. Maximum heart rate
16. Baroreflex sensitivity
17. Glucose tolerance
18. Maximum oxygen consumption
19. Naming
20. Speed of information retrieval from memory

There are, by contrast, a number of organ functions which have been shown not to decline with age. Some of these remain constant across the age spectrum, and a few increase. Functions which do not change with age include:

1. Fasting blood sugar
2. Electrolyte composition of the blood
3. Blood pH
4. Hematocrit
5. Leukocyte and platelet counts
6. Cardiac output
7. Levels of several hormones (insulin, cortisol, thyroxine, parathormone)
8. Cognitive function

A few parameters actually increase with age, though not necessarily to the benefit of older persons:

1. ADH response to physiologic stimuli
2. Blood pressure
3. Stroke volume
4. Suppressor T cell numbers and function
5. Auto anti-idiotypic antibody production
6. Prostate gland mass

Impact of aging on disease

Under-reporting of symptoms: A phenomenon partly responsible for advanced disease states producing disability in frail elderly is the failure of many old people to report legitimate symptoms of serious but treatable disease. The first reports of this behavior came from Scotland where, in the 1950s and 1960s, pioneer geriatricians screened elderly individuals, seeking information about illness behavior. In spite of comprehensive, free health services provided by the government, startling numbers of serious problems unknown to and untreated by the patient's physician were discovered. The disorders were obvious and not at all difficult to detect. Frequently encountered problems included decompensated heart failure, correctable hearing and vision deficits, active tuberculosis, urinary incontinence, severe anemia, chronic respiratory insufficiency, claudication, cancers, nutritional deficiencies, uncontrolled diabetes, foot disease preventing mobility, oral disease hampering eating, dementia, and depression.

The most common explanation for the elderly tolerating and not reporting symptoms was the common belief that old age always is associated with illness, loss of independence, and feeling sick (sick = old). This ageist view of senescence guarantees that older individuals, even when afflicted with the same symptoms which impel the middle-aged sick into the mainstream of the health care system, will not seek care, will silently suffer progression of disease, and will lose independent function. Good clinical research has shown repeatedly that old age, free of disease, is a time for feeling well and continuing function. But while ageism and ignorance of gerontologic information persist, elders will continue to expect discouraging decline. Sick old people are sick because they are sick, not because they are old. Although physiologic decline characterizes much normal human aging, these declines are gradual, and their functional impact is softened by the decades over which they occur and by the sizeable biological reserve capacities of humans. Thus, major functional decline, especially if abrupt, in an elderly individual, is usually due to disease, not aging.

Another reason for the elderly not reporting illness was that depression is not uncommon, and interferes with desire to regain vigor. A third explanation was intellectual loss. While dementia is never normal, it is more prevalent with age and interferes with a person's ability to identify and express symptoms of an illness. And regrettably, these unfortunate old people also are evaluated by their physicians less enthusiastically for associated medical disease. A fourth explanation for symptom concealment by elderly patients was fear that something would be found which, when treated, would produce functional loss and jeopardize independent living.

Failure to report symptoms reflecting underlying disease by the elderly is especially dangerous given the structure of our health care system. American health care, although excellent, is passive, especially for elderly people, and lacks prevention or early detection efforts. American hospital beds, physicians' offices, HMOs, emergency rooms, and neighborhood health centers all wait for the symptomatic patient to activate the system. This system of care is adequate for children, who have parental advocates, and adults through late middle age who have work and family responsibilities impelling them to seek medical care for symptoms. But aged persons, without advocates and usually without jobs, burdened by society's and their own ageist views of functional loss in the elderly, cannot be relied upon to initiate appropriate health care for themselves, especially early in the course of an illness when intervention is most likely to have a favorable outcome. Our health care system relies on the patient to initiate care; and that is precisely what aged individuals do not do. This makes undetected decline especially likely among the sick elderly. Adding a more active case-finding facet for the elderly to our system would address the problem.

Multiple pathology: Another factor predisposing elderly individuals to decline due to late detection of illness is clustering of diseases in aged patients. Surveys of community-dwelling elderly have found, on the average, nearly five important disabilities per person, and institutional studies find more than double these figures. American clinical experience has enumerated the most common problems coexisting in elderly individuals (Table 1).

Common Problems Coexisting in Elderly Individuals

1. Congestive heart failure
2. Depression
3. Dementia syndrome
4. Chronic renal failure
5. Angina pectoris
6. Degenerative joint disease
7. Gait disturbance
8. Urinary dysfunction
9. Constipation
10. Vascular insufficiency in the legs
11. Diabetes mellitus
12. Chronic pain
13. Sleep disturbance
14. Multiple drug regimens
15. Anemia

TABLE 1

The number of diseases per individual is strongly age-related, rising to more than a dozen in the very old. If the multiple pathologic conditions are not identified, diagnostic or therapeutic interventions are likely to harm rather than benefit the patient. Silent, untreated diseases create reverberating stress in all involved organs and tissues, producing new and further deterioration. As each overburdened unit declines, an irreversible concatenation of deteriorations develops, passing multiple points of no return, leading to infirmity, dependence, and if uninterrupted, death. But proper management, which considers the impact of treatment for one disease on the other coexisting illnesses, can be effective in maintaining function and life quality.

Diseases of the Elderly: Diseases in old age can be divided into two broad groups. The first group consists of disorders which, whether rare or common, are usually encountered only in the elderly. The second group includes diseases which, though occurring in patients of varying ages, present unusual features in the elderly. Diseases and disorders common in elderly patients are given in Table 2.

Problems More Common or
Severe In The Elderly

1. Falls
2. Syncope
3. Hip fracture
4. Urinary incontinence
5. Fecal incontinence
6. Fecal impaction
7. Pressure sores
8. Hearing and vision impairment
9. Stroke
10. Dementia syndrome
11. Parkinsonism
12. Normal pressure hydrocephalus
13. Polymyalgia rheumatica/giant cell arteritis
14. Osteoporosis
15. Osteoarthritis
16. Paget's disease
17. Carpal tunnel syndrome
18. Spinal stenosis
19. Diabetic hyperosmolar nonketotic coma
20. Inappropriate ADH secretion
21. Accidental hypothermia
22. Chronic lymphatic leukemia
23. Basal cell carcinoma
24. Angioimmunoblastic lymphadenopathy with dysproteinemia
25. Solid tumors
26. Tuberculosis
27. Herpes zoster
28. Arteriosclerosis
29. Amyloidosis
30. Colonic angiodysplasia
31. Isolated systolic hypertension
32. Postural hypotension

TABLE 2

Diseases with unusual presentation in old age: The second and much larger group of diseases comprising geriatric medicine are those which, though occurring in patients of all ages, behave differently in the elderly. A fundamental principle in caring for aged individuals is that virtually any disease with a classic complex of symptoms or signs frequently presents in old age with few or none of the characteristic findings. The classic presentation is often replaced by one or more prosaic non-specific problems. The commonest are refusal to eat or drink, falling, incontinence, dizziness, acute confusion, a new or worsening dementia syndrome, weight loss, and failure to thrive. Any of these occurring in an elderly person usually heralds the onset or worsening of disease, and should never be attributed to old age. Certain diseases are especially likely to be enigmatic in the elderly (Table 3).

Diseases Likely to Present Non-
Specifically in the Elderly

Pneumonia
Meningitis
Tuberculosis
Myocardial infarction
Pulmonary embolism
Digitalis toxicity
Myxedema
Alcoholism
Accidental hypothermia

TABLE 3

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HEALTH ISSUES IN AN AGING SOCIETY: THE RESEARCH AGENDA

David Mechanic, Rutgers University

Several years ago, Dr. DeWitt Stetten, Jr., a distinguished physician and science administrator at the NIH, wrote in the New England Journal of Medicine about his frustrating experiences in coping with his increasing blindness due to macular degeneration. Throughout his career, Stetten had been a vigorous proponent of biomedical science and its applications. When personally confronted with an irreversible disease and a loss of function he discovered how little he was assisted by physicians who were interested in vision but not in blindness. He found to his dismay that he received little help from his cherished profession in preserving his ability to function. As he lamented, "through all these years, and despite many contacts with skilled and experienced professionals, no ophthalmologist has at any time suggested any devices that might be of assistance to me. No ophthalmologist has mentioned any of the many ways in which I could stem the deterioration of the quality of my life."

Stetten was a resourceful person, and through his efforts and inquiries he discovered many ways of making his life more bearable and productive. What Stetten tells us about blindness is applicable to every specialty in medicine and every chronic disease. The almost exclusive focus of medicine on disease in contrast to the person, and the failure to give sufficient attention to function and quality of life describes the experience of far too many patients with heart disease, cancer, mental illness, and the like.

No sensible person denigrates the remarkable contributions of science, or the possibilities it offers. But science does not prescribe our values or focus nor is applicable only to cure. In chronic disease, and increasingly in an aging society, the challenge is to intervene in illnesses that have developed over a lifetime and to minimize their impact on well-being and performance of valued activities. The quality of a health system is truly measured not by what it spends, or the number of sophisticated procedures it performs, but how it enhances the potential of the population to fulfill its personal and social choices and the extent to which it limits suffering. In monitoring the health of the nation, this should be our focus and priority.

By the end of World War II the attention of medicine had increasingly turned to the chronic diseases, clearly the major cause of morbidity and mortality in the nation. When Congress, in 1956, passed the National Health Survey Act, establishing a continuing survey of illness and disability, chronic conditions were high on its agenda, and the Act specifically and prominently notes the need for the latest information on heart disease, cancer, diabetes, and arthritis and rheumatism. The aging of the American population was not yet salient, and the dramatic improvements in longevity beginning in the middle 1960's were not anticipated. Yet, the Act itself gives great prominence to "research in the field of chronic disease," measurement of inability to perform gainful work because of disability, the length of disability, services consumed, and the economic impact.

This Act culminated in the development of the most sophisticated and comprehensive programs of data collection on health anywhere in the world, and it has contributed enormously to our understanding of American health care. But despite the interest in chronic disease that motivated the establishment of the National Health Survey and its development, the underlying paradigm was one that continued to be shaped by conceptions of acute disease, short episodes of care, and relatively simple and narrow depictions of care processes. Part of this emphasis was a product of the limits of measurement and methodology which restricted the conditions and processes that researchers thought they could reliably measure with the tools at hand. The health problems of an aging society, however, compel us to examine illness and disability in a much broader context than ever before not only to better understand the links between aging and health but also to effectively monitor the health of the nation in terms of our most important aspirations.

There is no need to reacquaint this audience with the demographic facts of aging, or with the gains in longevity achieved in the past 20 years. The practical issues we face are less concerned with enumerating illnesses, doctor visits and hospital stays, although these are not unimportant, and more with describing the quality of life, the range of function, and the needs for care and assistance among our oldest citizens and others with disabling diseases and conditions. Our focus must shift from a static picture and acute instances to a longitudinal portrait and sequences of care over time. In chronic disease, the inputs prior to hospitalization and the care following it are as important as the hospital admission, and what happens before and after are critical in the evolution of illness sequences, the inputs of care needed over time, the quality of outcomes, and the costs of care. Knowing about hospital stays without information on subsequent nursing home admission, or knowing who comes to nursing homes but little about who stays and leaves, and under what circumstances, provides a picture too incomplete for the profound issues our society and our government must address in the coming years.

By design, the National Health Surveys were intended to service a heterogenous population of users and to cover a wide array of health issues. Thus from the first, these surveys were limited in the intensity they could probe any single issue or in their ability to speak to questions involving small geographic areas or subgroups of the population limited in size. In the past 30 years our medical care system has multiplied in size and in its complexity, but the magnitude of our data collection efforts have not kept pace with the evolution of the health care system. The health statistics budget is far too small to allow collection of the needed data in a timely fashion, to repeat important surveys at necessary intervals, and to provide estimates for subgroups of the population that may be small but essential to making good health policy. It is appalling that until the repeat in 1985 of the Nursing Home Survey, whose data are only becoming available now, we had to depend on survey results ten years old to tell us about the characteristics of persons in nursing homes and long-term care needs. Similarly, until recently, we had little data that pertain to our most elderly subgroups (the oldest-old) and until the very recent Hispanic HANES we could not provide any reasonable picture of differentiation among Americans of hispanic origins. Focussing even more specifically, we know relatively little about the special health problems of the elderly mentally ill, the uninsured, the homeless, minority groups other than blacks and hispanics, and those with serious longterm chronic diseases of many specific kinds. Good policy depends not only on knowing central tendencies and trends but also on understanding the special problems of those who fall through the cracks.

In coming years, aging policy issues will be high on the nation's agenda and will require sophisticated data to assess the scope of varying problems and the degree of heterogeneity in an aging population. There are many worlds of aging and a high degree of specificity is required if we are to target resources in a cost effective way. The size of the aging population, and its needs, will make large demands on government budgets; estimates of averages will not provide the data required to develop responsive public policies or to design appropriate delivery systems.

A major advance in aging research has been the growing awareness of the importance of the birth cohort, and appreciation that even cohorts relatively close in historical time may have widely varying opportunities and very different health outcomes as they progress through the life cycle. A major Swedish longitudinal study of three elderly cohorts, for example, found "marked differences both in manifestations of aging and in the state of health between [these] three cohorts which are separated by intervals of only five years" (pp. 195-196).

The cohort, both as a theoretical and methodological concept, uniquely fits a lifecourse perspective which examines individuals and the important units they compose (such as households and families) within a longitudinal frame of reference. Experience at any point in the life cycle is influenced by earlier experiences and choices that affect the probabilities of later pathways. These perspectives, particularly as they apply to health and the influences of health behavior on health outcomes, alert us to the shortcomings of static conceptions derived from cross-sectional studies, and make clear the importance of examining health status over time, patterns of care, sequences of illness episodes, and the linkages between need and receipt of varying components of care. A cross-sectional view offers limited understanding of complex utilization trajectories within any aspect of health services over time, much less how utilization occurs among interconnected health and social services.

Longitudinal studies are, of course, difficult and expensive to execute and most need to be supported through special grants and contracts. But increasingly the NCHS will have to consider, as well, the role of longitudinal studies in its overall program. Carrying out such studies on a national basis, in contrast to some limited sampling areas, may not provide sufficient information on the context of care to depict adequately the processes of central interest, and the emphasis on national studies may have reinforced a sense of cautiousness in moving into some of these new endeavors. But such efforts are necessary nevertheless.

The Health Interview Survey and the Hospital Discharge Survey have allowed us to monitor access to physician services, numbers of visits, hospital admissions and surgical procedures and perceptions of health and need on a national basis for varying major socio-demographic groups. There are limits in the accuracy of respondent reports, but the Health Interview Survey assists us in constructing a portrait of the nation's health. In contrast, it is not designed to tell us a great deal about access to specialized services among persons with comparable levels of need or about the content of care and its appropriateness. The National Ambulatory Care Survey provides a more complete picture of the content of care, and how it varies by medical specialty, but it is not sufficiently sensitive to provide a basis for assessing whether the care provided is appropriate to levels of need or equitably distributed. There are extraordinary technical difficulties, but we will have to find better ways of linking major national sources of information.

We need to learn a great deal more about the content of care and its link to broad outcome measures. As cost constraints grow, as in the case of DRG's and other forms of prospective reimbursement, there will be increasing necessity to examine such issues as the appropriateness of care, discharge trends, and underservice more carefully than in the past. Data presently collected allow comparisons of the frequency of use of physicians and other services among populations varying in age, income, and race or ethnic status. But the data are not specific enough to assess differential access to such specialized services as state of the art cancer care or appropriate mental health services. For example, only 38 per cent of blacks with cancer survive for five years as compared with 50 per cent of whites. Black-white differences appear to be largest in cancers that are most amenable to treatment suggesting that access to sophisticated cancer care may explain some of these differences. But we have little data on differential access beyond very general measures.

As longevity of the population has improved, much debate has focussed on whether more recent elderly cohorts suffer less disabling disease as they progress through the later decades. The debate focusses on whether there is a natural death without an intervening period of substantial disability and incapacity. The data on this issue is inconclusive and, in any case, we should not assume a linear progression among succeeding cohorts. The evolving health status of any birth cohort depends substantially on the historical conditions it experiences, but these conditions may alter from one period, culture or geographic area to another. Moreover, we have no good way of anticipating new major health threats such as AIDS. Understanding the complex interactions between the life course and a changing environment should alert us to the hazards of assuming homogeneity within birth cohorts or linear outcomes among successive generations.

These concerns may seem less pertinent to health planning than to the scientific community. The burden of disability and dependence is a product of the rate of disease occurrence, the size of the populations at risk, and the course of disease. Even if the elderly are more healthy and vital than ever before, the size of elderly cohorts makes apparent very high impending levels of dysfunction and need requiring large societal inputs.

Much of the longterm care needed is better conceptualized as a process over time linking health facilities and community services than a set of traditional services. The quality of such care depends on concepts of community, networks of reciprocal obligation, and the interplay of competing and changing values among the generations. The process also depends crucially on the organization of households and other living arrangements, the increasing role of women in the labor force and flexibility in work schedules, and the coherence of community organization. An impressive proportion of care for the dependent elderly is provided by family members and other close associates. While the emerging debate will be focussed on developing a viable financial structure for longterm care protection, concern about the substitution of formal services for those now provided voluntarily will remain a powerful underlying issue. Whatever approach we develop must be sensitive to the evolving culture and consistent with its values. Thus, the discussion of longterm care must be informed by the best possible information on emerging values and social organization.

Longterm care for the elderly will be high on the public agenda in coming years, and increasing pressure will be placed on the federal statistical agencies to answer crucial questions concerning the magnitude of need, the course of dysfunction, and the pattern of services that respond meaningfully to quality of life issues.

Understanding the challenges of longterm care also requires attention to people's tastes and wishes. The more we learn about how patients, families and providers behave, the better we appreciate variations in values and ideologies, illness behaviors and perceived needs, family structures and availability of informal care-takers, and the part all of these differences have in either enhancing or interfering with effective care. We have a need to talk in generalities, and readily overlook the differences in capacities and preferences that characterize individuals. By examining issues more specifically, and good data helps enormously, we are better prepared to design services in a manner adaptable to the true heterogeneity of the populations served. Within reasonable ranges of cost and effectiveness, we should seek to design policies that enhance choice, since it increases satisfaction and compliance and limits conflict and disruption in services.

Health services in America is a gigantic and dynamic industry. The increasing complexity of competitive and regulatory strategies, the growing supply of physicians, the momentum in biomedical science and technology, the changing organizational arrangements among health providers, and the entry of large profit-oriented chains, contribute to a high degree of uncertainty and instability in the system. The efforts to place constraints on the system by government, by managers of health programs, and by employers as well who pay many of the costs, have jolted earlier power alignments and encouraged new types of partnerships. Organizations having similar designations vary among themselves and are also changing as the environments in which they function become modified. Those responsible for monitoring the health services system and its performance must keep pace with moving targets.

HMO's illustrate the point. Historically, prepaid group practices emerged from particular historical conditions, and a few major prepaid plans dominated this sector. Such plans as Kaiser-Permanente and HIP were organized to meet well-articulated needs, and were governed by high levels of administrative responsibility and commitment and thus could be viewed as having important common features. But such plans even 30 years ago varied in the proportion of patients cared for who were prepaid, ownership of hospitals, contracts with physicians, how providers were remunerated, and many other important features. As the HMO concept has expanded to include entities other than prepaid groups, and managers concerned as much about profits as care, it becomes clear that the concept has limited common meaning beyond its prepaid features. Prepayment, of course, is attractive to many large purchasers who seek to reduce costs in a predictable way, but the expansion of the types of organizations involved suggests the likelihood of much more variable performance.

As cost constraints accelerate, the issue of quality will become increasingly salient. With the implementation of prospective reimbursement in Medicare, despite its relatively lenient pricing policies, it is more commonly alleged that patients are prematurely discharged and that necessary care is being withheld. While thoughtful analysis has been given to issues of quality, the uncertainty of much of medical care, or even its most appropriate objectives, make measurement and assessment difficult. Incompetent care is relatively easily identified, but much of the variation falls within boundaries more difficult to define. Excellent technical care may not enhance function, and services that patients may find amenable to their preferences and appropriate to maintaining their desired activities may seem irrelevant to implicit medical standards. However difficult it is to measure quality, the issue is inescapable.

Many forces shape the evolution of health services but historical studies show that over the long-range the changing distribution of disease is a major determinant. It is inevitable that our health system will adapt however slowly to the demands of chronic illness and consumers' interests in types of care that best allow them to maintain function in normal social roles and living situations. Ultimately, quality of life issues will play a large part in the choice of alternative treatments, in the selection of alternative drugs, and in the contexts of care whether the hospital, the hospice, the nursing home, or the home. To choose wisely depends on understanding the consequences of varying regimens of care for medical outcomes, for the quality of function, and for costs. These issues deserve high priority on the future health research agenda.

Session A

Health Promotion and Disease Prevention

DATA FOR AN AGING POPULATION

ATTRIBUTABLE RISK OF MORBIDITY: A STRATEGY FOR FOCUSING PREVENTIVE HEALTH CARE FOR THE ELDERLY

Linda P. Fried, M.D.
Johns Hopkins University School of Medicine

(Not available for publication)

METHODOLOGICAL ISSUES IN EVALUATING CALIFORNIA'S PREVENTIVE HEALTH CARE FOR THE AGING PROGRAM

Philip G. Weiler, U.C. Davis; James E. Lubben, U.C. Los Angeles; Iris Chi, University of Hong Kong

Introduction

Recent studies have described the substantial range of potential contributions represented by more comprehensive preventive health programs targeted toward older Americans. Accordingly, many preventive health programs for older Americans have developed and been implemented over the past two decades. However, preventive health care for the well elderly has been difficult to evaluate, and few studies have attempted to measure the effectiveness or efficiency of these programs (Rubenstein et al.). This paper will examine some of the issues in evaluating one of the oldest and largest preventive health services for the elderly, PHCAP.

The Preventive Health Care for the Aging Program (PHCAP) was launched in 1973 in California with only three county health department pilot projects. By 1985, the total number of projects had risen to 24. The PHCAP is a statewide program which provides health maintenance, disease prevention and health promotion services to ambulatory Californians 60 years of age or older. These services are provided primarily by public health nurses in local public health department jurisdictions.

Basic to the PHCAP is a public health nurse's encounter with the older adult. For each participant's visit, the nurse completes an encounter form which collects information on the participant's demographic data and health status as summarized in Table 1. The total number of participants and visits to the PHCAP program for 1983 - 1986 are depicted in Table 2. As shown in Table 3, about half of the participants make only one visit and 10% have five or more visits. The mean number of visits is 2.2. Older participants tend to visit more often than younger participants.

In 1986, after the program had been in operation for 13 years, the University of California, Davis was asked to initiate an evaluation of PHCAP. The original purpose of the evaluation was to determine, within the constraints of existing data, the effectiveness of the PHCAP services. An additional consideration was the concept of efficiency. This was defined in terms of what procedures were resulting in the highest rate of new problem identification; was the targeting of services appropriate; and which problems were resulting in the highest rate of referrals to physicians.

Data System

The PHCAP data system contained eight tapes, developed from the initiation of the computer program in 1983 through 1986. Because of the magnitude of the data (more than 82,000 participants and 200,000 visits), it was decided to work with only one fiscal year, 1985-86. The 85-86 tape was then converted from a raw rectangular data file into five SAS system files. The original tape had over 47,000 case records; however, about 2300 of these records were immediately eliminated from the sample because they were non-visits (i.e., referral, drop out or deceased.) Another 183 records were eliminated due to missing data (i.e., gender data) which were required to get an unduplicated count. Thus the initial sampling frame consisted of over 45,000 records. A simple 30% random sample was drawn from the population that included all PHCAP client visits made in the program year 1985-86 for a total sample size of 5,454. Major characteristics from this sample are shown in Table 4. Table 5 shows basic health status data of the PHCAP population.

Methodological Issues

There were several methodological issues involved with this study. Some problems were generic to the use of large data bases in health care studies (eg. costs for analyzing the data and the large number of variables) and have been well described (Connell, Diehr, Hart). Other problems occurred because the PHCAP was initially set up as a public service program responding to a perceived need in the community, and, therefore, was not set up in an experimental fashion to accurately test its effectiveness. However, this is not an unusual situation, and frequently researchers must deal with this type of issue.

1)Sampling: The data storage and processing costs of this large a data base required sampling. Even with a 30% sample, data storage costs were $30 a day. Using the first record for everyone represented 14,000 people and would have increased costs. In addition, this would not allow for longitudinal analysis. In order to draw a sample, all records had to be read. This cost was as much as $100/run.

Another factor was not only costs but time. As time required for a run increases, the priority on the computer queue is lowered. To get an accurate sample, an unduplicated count had to be constructed. First, a new unique identification number was created to overcome a problem with duplicated identification numbers across project sites as well as a deliberate sharing of numbers in some sites for spouses. Then all records were sorted by this new identification number and a random number was assigned to each record using the SAS random number function for a uniform probability distribution (0-1). This random number was retained for all records with the same identification number (i.e., each participant was assigned the same random number for all records of that particular participant). Thus, the sample is a sample of participants, not records. In cases of multiple visits, only the first record was selected for these tables.

2)Comparison group: Consideration was given to use of a nonequivalent control group from a national or state representative sample of the elderly population (e.g. the National Center for Health Statistics Health Interview Survey). Compared to national data, PHCAP participants were more likely to be widowed and less likely to be married. NHS data also show 30% elderly living alone whereas 43% of PHCAP participants lived alone. Compared to

California 1980 Census data, PHCAP participants have a greater percentage of female and are older than the state population as a whole. The ethnic distribution closely reflects that of the state elderly as a whole. However, these groups presented problems in comparability and in data obtained.

Other possible comparison groups considered included the California Senior Survey (a random sample of Medicaid recipients), the UC Davis Medical Center Geriatric Clinic, a comparison group from an HMO, or from other public health clinics. None of these other comparison groups turned out to be feasible because of the incompatibility of the data sets collected, the self-selection bias of PHCAP, different health or socioeconomic status of the population, or the difficulty and expense of obtaining the data which were not computerized or centralized in any way. In addition, there was no way of knowing, even with a comparison group, what other interventions beyond PHCAP the elderly had access to. Because of these difficulties, the concept of any external comparison group was dropped and we decided to compare the PHCAP participants with themselves and to determine changes in outcome measures over time.

Several internal comparisons were possible. We compared "new" vs. "previous" evaluations. The results of such comparisons are shown in Table 6. Although these data are hard to interpret, one could assume that "new" participants should have more areas assessed and more problems detected and referred. This was the case for vision referrals, hearing referrals, and blood pressure referrals. However, many areas showed no significant difference and some areas were assessed more frequently in previous participants than in new participants (e.g. blood pressure, genitourinary and gynecology). This could also represent a change in health status of returning participants. Other internal comparisons included men versus women and young old versus old old.

3)Outcome measures: In a well-designed experimental trial, outcome measurements are determined beforehand, but in a clinical program they are not. We decided to use modifiable risk factors. Risk factors which we decided to study included nutritional status (i.e. salt intake), immunizations, abnormal lab results, eye problems, hearing problems, blood pressure, smoking, alcohol and weight control.

Even these presented problems because immunizations and smoking were rarely assessed (related to the way problems were defined). For example, smoking was only considered a problem if excessive and symptoms were present. In addition, although eye and hearing problems may be correctable, it is likely that they would still be considered problems even after being corrected.

4)Reliability and validity: There was a need for developing consistency of system assessment across various projects. For blood pressure, for example, some sites were taking it with the participant lying down, sitting and standing, in one or both arms, and others were not. Laboratory tests also varied quite markedly. Urinalysis in some programs included occult blood, albumin, glucose and microscopic, and in others only glucose. The state also had developed standards for referral. However, these were interpreted in different fashions at each project. These variations affected the validity and reliability of the data. To overcome this, a survey was made of each of the projects and more explicit staff standards were developed for patient assessment and referral. Caution was also used in interpreting data in areas of inconsistency (e.g. nutrition, 24 hour recall vs. food frequency) and of low frequency (e.g. neurology and endocrine assessments).

5)Denominator problems: For each system assessed, a denominator needed to be determined to calculate percent of participants with problems. The options were using the entire sample as the denominator (both assessed and not assessed), or only using those assessed as the denominator. Since the real issue for public policy seemed to be how many that were assessed turned out to have problems, it was decided to use as the denominator only those assessed for a particular problem. This resulted in a low of problem identification of 10% for psychosocial to a high of 24% for genitourinary.

6)Rare events: The analysis of referrals (i.e. rare events) had to be limited to the "top ten" (Table 6) in order to have a sufficient number of problems for referrals. It was decided to analyze percentage of referrals over those with problems. The percentage of referrals to physicians was also calculated to determine which problems were viewed by PHCAP nurses as being appropriate for physician referrals. Sometimes men were more often referred than women (e.g. blood pressure, oral/dental, hearing, vision). Younger participants were more often referred for hearing and OB/GYN, but older clients for musculoskeletal. Most physician referrals (45%) were for vision problems and least for nutrition (2%) and for psychosocial (3%).

7)Missing data: Several assumptions could be made regarding rate of problem detection among the unassessed: a) the rate was the same as the assessed, b) based on marginal rate of return, rate was even lower in unassessed (i.e. targeting), c) those unassessed have a higher rate (not as plausible).

Preliminary findings seem to indicate that there may indeed be an age and gender bias in the assessment process. Targeting most often occurred in terms of age and generally younger elderly were assessed most often. Sometimes this resulted in good targeting, but often it was inappropriate to assess the younger elderly more because the rate of problem detection was significantly greater for the oldest age group. Examples of this type of inappropriate targeting were vision, hearing, cardiovascular, and skin screening. All three types of laboratory tests (urinalysis, HGB/HCT, and blood sugar) were also inappropriately targeted to the youngest group when older participants were more apt to have a problem detected.

8)Determining new problems: New problems were determined by juxtaposing self-assessed and assessed problems. Table 7 compares self report data on hypertension with problem detection and also four other chronic conditions that were similar on self report with areas assessed on the encounter form. A "new problem" is one in which the self report indicated no such condition existed but one was found at the time of the actual health system assessment. These data show the relative rate of such new problem detection for annual, new, and revisits. Obviously, revisits seem very "targeted" and are thus quite capable of finding new problems (probably responding to participant complaint). New clients are more apt than "annuals" to have a new problem discovered. This too makes sense in that "annuals" probably have had "surprises" already discovered at earlier visits. Hypertension does not fit the pattern, perhaps, because of greater awareness in community and less tendency for under-reporting.

The last two issues are briefly discussed. Visit variations (initial, annual, revisit) were addressed by cross-sectional sampling of patients disregarding type of visit and by subsampling for comprehensive visits only. Longitudinal data were obtained using a unique identifier to examine change in problems over time and risk factors.

Summary

Frequently, when programs have been instituted to address a specific public demand and service clinical need, it is impossible to retroactively change the design of the program to conform with acceptable experimental design and program evaluation standards. Because this occurs often in publicly funded programs, it is essential that investigators learn to adapt data analyses for such programs if policy makers are to obtain the most useful scientific data for decisions. There are two basic issues to be examined. One addresses effectiveness and requires some type of comparison group. The other issue is efficiency and addresses targeting and normative data. Approaches to such problems are illustrated by the California PHCAP. One approach is to examine the data collected and, if it is a large data set, attempt to work with only a small sample of the data. Second, it is important to establish an unduplicated count and, if required, search secondary sources to assure this by using such items as sites within programs, year of birth and gender. Third, several variables in a program may be either very nonspecific or infrequent. These variables have to be changed or consolidated into more meaningful variables, which have a higher frequency of assessment and are standardized across program sites. Next, if an external comparison group is not possible, due to funding restrictions, lack of accessibility, or other reasons, then other methods will have to be developed, such as internal comparisons and longitudinal comparisons for changes in risk factors, or health care utilization.

Another advantage to analyzing such data as PHCAP is the development of normative data for participants going to preventive health programs. These data may be useful for other preventive programs for comparison.

For policy makers, the option that a program cannot be evaluated because it does not meet certain scientific standards, is frequently not a viable political one. Therefore, given an ongoing program, with existing data constraints, one needs to determine what is the most useful information about program efficiency and effectiveness that can be obtained.

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Table 1: Preventive Health Care for the Aging - Areas Assessed

1. Demographic/Social
   - date of birth
   - sex
   - living arrangements
   - ethnic group
   - marital status
   - medical coverage

3. Dietary
   - 24-hour recall
   - Congregate meals per week

4. Blood pressure
   - systolic
   - diastolic

5. Chronic diseases known to client

6. Disability
   - Hospitalizations in last 12 months
   - Bed days last month

7. Most common health systems assessed
   - Blood pressure
   - Eye
   - Skin
   - Musculoskeletal
   - Oral/Dental
   - Genitourinary and gynecology
   - Cardiovascular
   - Gastro-intestinal
   - Respiratory
   - Hearing

8. Laboratory screening
   - Urinalysis
   - Hgb/Hct
   - Blood sugar

9. Health counseling
   - Immunization
   - Nutrition
   - Psychosocial
   - Weight
   - Exercise
   - Medication
   - Breast examination
   - Smoking
   - Alcohol
   - Medical supervision

10. Referral results
   - source of referral
   - outcomes
   - new diagnosis
   - new treatment

Table 2
TOTAL PARTICIPANTS AND VISITS TO PHCAP

Program Year	Number of Participants	Number of Visits
1983-84	31,868	82,745
1984-85	31,103	79,996
1985-86	16,906	45,405

Table 3
1985 - 1986 PHCAP SERVICES by Gender and Age Category
Percent Distributions

					Men				Women			
	Total	Men	Women	(X^2) prob.	60-69	70-79	80+	(X^2) prob.	60-69	70-79	80+	(X^2) prob.
All Persons	100	34	66		39	49	13		37	48	15	
(N)	(5454)	(1859)	(3595)		(715)	(909)	(235)		(1339)	(1734)	(522)	
Number of visit												
One	43	44	43		48	43	37		47	41	37	
Two	24	24	25		25	22	25		26	24	22	
Three	13	13	13		12	14	11		13	13	12	
Four	7	6	7		6	6	8		6	7	9	
Five or more	13	13	13	(2.3)e	10	15	18	(21.5)b	8	15	20	(63.2)a
(Mean # of visit)	(2.5)	(2.5)	(2.5)		(2.3)	(2.6)	(2.9)		(2.2)	(2.6)	(2.9)	
Received comprehensive PHCAP examination	75	75	75	(.0)e	78	73	71	(7.5)c	78	73	74	(11.4)b

Table 4: Major Characteristics by Gender and Age Category - Percent Distributions

					Men				Women			
	Total	Men	Women	(X^2) prob.	60-69	70-79	80 +	(X^2) prob.	60-69	70-79	80 +	(X^2) prob.
All Persons	100	34	66		39	49	13		37	48	15	
(N)	(5454)	(1859)	(3595)		(715)	(909)	(235)		(1339)	(1734)	(522)	
MAJOR CHARACTERISTICS												
Mean Age	(71.9)	(71.8)	(72.0)		(65.3)	(74.2)	(82.3)		(65.1)	(74.2)	(82.2)	
Ethnicity												
White	83	81	85		78	83	83		81	86	90	
Black	3	3	3		5	2	2		3	4	2	
Hispanic	9	9	9		12	8	8		11	7	5	
Other	5	6	4	(21.3)a	5	7	8	(26.2)a	5	3	3	(36.5)a
Marital Status												
Married	51	74	39		76	74	65		53	36	14	
Widowed	37	13	49		9	14	25		33	52	78	
Sep/Divorce	9	8	9		10	7	7		10	9	5	
Other	4	5	4	(464.1)a	5	5	4	(42.6)a	4	3	3	(309.5)a
Living Arrangement												
Alone	41	22	51		19	22	29		37	55	74	
Family	57	76	47		78	76	69		61	43	23	
Other	2	2	2	(423.0)a	3	2	3	(9.3)d	2	2	3	(228.6)a
Residence												
Urban	58	54	60		51	56	55		52	63	68	
Semi-urban	22	23	21		25	23	18		25	20	18	
Rural	20	23	19	(17.1)a	24	21	26	(9.2)d	23	17	14	(54.3)a

a p<.001
b p<.01
c p<.05
d p<.10
e Not Significant

Table 5: Health Status by Gender and Age Category - Percent Distributions

							Men						Women	
	Total	Men	Women	(X^2) prob.	60-69	70-79	80+	(X^2)	prob.	60-69	70-79	80+	(X^2)	prob.
All Persons	100	34	66			39	49	13			37	48	15	
(N)	(5454)	(1859)	(3595)			(715)	(909)	(235)			(1339)	(1734)	(522)	
Hospitalized														
0 day	88	87	89			91	85	83			92	87	85	
1-6 days	7	8	6			6	8	9			5	7	8	
7 + days	5	5	5	(3.4)e		3	7	8	(15.2)b		4	6	7	(21.3)a
Last time saw doctor														
3 months or less	49	46	50			41	50	50			46	53	56	
3-6 months	15	14	16			14	14	14			15	16	16	
6-12 months	13	13	13			13	12	13			14	13	13	
1-2 years	11	13	9			15	12	13			10	9	9	
2 + years	12	14	11	(32.1)a		17	13	10	(19.8)c		15	9	6	(50.1)a
Chronic Diseases														
Arthritis	31	23	35	(72.3)a		24	25	18	(5.1)d		33	36	35	(3.6)e
Stroke	2	3	2	(6.8)b		2	4	3	(2.8)e		1	2	4	(11.7)b
Cardiovascular	13	14	13	(2.9)d		13	16	13	(3.2)e		11	13	17	(14.7)a
Diabetes	6	7	5	(2.5)e		8	5	5	(7.4)c		5	5	7	(1.9)e
Hypertension	24	21	26	(12.3)a		23	21	17	(3.2)e		23	27	28	(9.3)b
Respiratory	6	7	6	(1.5)e		6	8	5	(0.5)e		7	5	4	(5.9)d
Vision	18	17	18	(1.0)e		15	17	22	(5.7)d		15	19	24	(23.7)a
Hearing	11	15	9	(46.8)a		13	15	23	(14.3)a		8	8	15	(21.6)a
# Of Chronic Diseases														
None	44	46	43			46	46	50			46	42	38	
1	23	22	24			24	22	19			24	23	23	
2	17	17	18			16	18	15			18	18	17	
3 or more	16	15	16	(4.9)e		15	15	16	(5.3)e		12	17	22	(31.7)a
(Mean #)	(1.1)	(1.1)	(1.1)			(1.0)	(1.1)	(1.1)			(1.0)	(1.2)	(1.3)	

Table 6: Problem Detection and Referral Gender and Age and New Clients Category
Percent Distributions

		Total	Men	Women	(X^2)	60-69	70-79	80 +	(X^2)	New Client	Prev.Client	(X^2)
All	(N)	(5454)	(1859)	(3595)		(2054)	(2643)	(757)		(2048)f	(1452)f	
Persons	%	100	34	66		38	49	14		59	41	
Vision												
% assessed		62	61	62	(.2)e	65	60	58	(20.2)a	87	85	(1.2)e
% pbm|assess		22	22	22	(.1)e	19	22	30	(24.2)a	20	18	(.9)e
% ref|pbm		66	67	66	(.1)e	70	67	58	(5.6)d	79	64	(14.6)a
% ref to MD		45	47	45	(.2)e	46	45	44	(.2)e	54	43	(6.3)c
Hearing												
% assessed		54	55	54	(.3)e	59	52	52	(24.6)a	80	80	(.0)e
% pbm|assess		16	23	13	(47.9)a	15	16	22	(12.3)b	16	14	(2.1)e
% ref|pbm		58	59	58	(.1)e	60	61	47	(6.1)c	65	53	(5.7)c
% ref to MD		26	25	26	(.0)e	26	27	21	(1.6)e	28	22	(2.1)e
Oral/Dental												
% assessed		56	55	56	(.4)e	60	54	53	(19.3)a	79	78	(.9)e
% pbm|assess		18	18	18	(.0)e	19	18	16	(2.2)e	15	16	(.2)e
% ref|pbm		61	64	60	(.9)e	59	61	71	(3.3)e	71	63	(3.0)d
% ref to MD		12	9	13	(2.5)e	11	12	13	(.1)e	13	11	(.5)e
Genitourinary & Gynecology												
% assessed		53	49	55	(14.3)a	57	50	52	(18.0)a	73	76	(4.8)c
% pbm|assess		24	15	28	(59.2)a	25	23	27	(3.8)e	25	17	(26.3)a
% ref|pbm		61	58	62	(.5)e	65	60	54	(4.1)e	67	61	(1.9)e
% ref to MD		39	45	37	(2.7)e	40	38	35	(1.0)e	42	38	(.7)e

a $p<.001$
b $p<.01$
c $p<.05$
d $p<.10$
e Not Significant

Table 6 (cont.): Problem Detection and Referral Gender and Age and New Clients Category
Percent Distributions

	Total	Men	Women	(X^2)	60-69	70-79	80 +	(X^2)	New Client	Prev.Client	(X^2)
All (N)	(5454)	(1859)	(3595)		(2054)	(2643)	(757)		(2048)f	(1452)f	
Persons %	100	34	66		38	49	14		59	41	
Blood Pressure											
% assessed	90	89	90	(.5)e	90	89	90	(.7)e	95	98	(32.7)a
% pbm|assess	19	20	18	(1.2)e	20	18	21	(5.9)d	17	17	(.0)e
% ref|pbm	48	54	45	(6.2)c	56	43	45	(13.0)a	68	46	(29.3)a
% ref to MD	25	25	25	(.0)e	27	22	27	(2.9)e	30	23	(3.4)d
Musculo-Skeletal											
% assessed	56	55	57	(.7)e	59	54	55	(11.4)b	77	77	(.0)e
% pbm|assess	21	20	22	(1.1)e	19	22	26	(10.7)b	19	20	(.1)e
% ref|pbm	44	45	43	(.2)e	42	47	40	(2.8)e	46	47	(.1)e
% ref to MD	16	18	15	(.6)e	20	15	12	(3.8)e	16	15	(.2)e
Skin											
% assessed	57	58	57	(1.2)e	61	55	54	(22.9)a	80	81	(.2)e
% pbm|assess	18	22	16	(20.4)a	17	18	20	(1.2)e	16	13	(4.5)c
% ref|pbm	63	64	63	(.0)e	67	62	58	(2.6)e	74	66	(2.5)e
% ref to MD	46	46	45	(.1)e	47	46	41	(.9)e	52	47	(1.1)e
Weight Control											
% assessed	77	77	77	(.1)e	79	76	76	(5.2)d	89	95	(33.0)a
% pbm|assess	13	11	14	(5.6)c	15	12	10	(11.3)b	10	13	(8.3)b
% ref|pbm	33	34	33	(.0)e	35	32	30	(.8)e	40	35	(1.0)e
% ref to MD	4	4	3	(.3)e	4	4	2	(.8)e	6	4	(.5)e
Nutrition											
% assessed	70	69	71	(2.7)e	71	69	70	(2.8)e	79	88	(46.7)a
% pbm|assess	22	23	22	(1.0)e	24	21	21	(7.8)c	24	22	(1.0)e
% ref|pbm	61	60	62	(.3)e	63	60	62	(1.1)e	64	66	(.4)e
% ref to MD	2	3	2	(2.5)e	3	2	0	(3.4)e	2	1	(1.5)e
Psychosocial											
% assessed	100	100	100		100	100	100		100	100	
% pbm|assess	10	8	11	(20.1)a	12	9	8	(17.9)a	10	12	(3.9)c
% ref|pbm	37	41	35	(1.4)e	37	36	40	(.4)e	42	42	(.0)e
% ref to MD	3	2	3	(.1)e	2	2	7	(5.3)d	3	3	(.1)e

a $p<.001$
b $p<.01$
c $p<.05$
d $p<.10$
e Not Significant
f Only clients who received a comphrehensive examination are included (Revisits are eliminated)

Table 7: New Problem Detection by PHCAP Nurses
Percent Distributions

	Hypertension	Cardiovascular	Respiratory	Hearing	Vision
% assessed	90	50	47	54	62
% w/problem (of those assessed)	17	9	8	15	19
% w/new problem (of those assessed)	7	4	4	10	11
New Problem Detection by Contact Type:					
Comphrensive Exam (New Client)	9	5	5	10	14
Comphrensive Exam (Previous client)	5	4	3	6	8
Revisit (Not Comphrensive Exam)	9	12	7	24	34
X^2, Prob.	(23.2)a	(38.2)a	(13.0)b	(67.7)a	(158.3)a
Refer to MD by Contact Type:					
Comphrensive Exam (New Client)	22	49	18	26	41
Comphrensive Exam (Previous client)	21	36	31	25	43
Revisit (Not Comphrensive Exam)	20	35	20	37	29
X^2, Prob.	(.2)e	(2.8)e	(1.9)e	(2.0)e	(5.5)d

Note: new problems are problems identified by nurses but not self-reported by client.

SCORING PHYSICAL ACTIVITY DATA WITH SPECIAL CONSIDERATION FOR ELDERLY POPULATIONS

Carl J. Caspersen, Robert A. Pollard,
S. Otis Pratt
Centers for Disease Control

Introduction

Physical activity has been identified as an important health-related behavior known to beneficially affect coronary heart disease (1), weight control (2), and symptoms of anxiety and depression (3). In addition, increased levels of physical activity may favorably affect hypertension (4), osteoporosis (4), noninsulin-dependent diabetes mellitus (4), some cancers (5, 6), and certain aspects of mental health such as the increased sense of well-being derived from feeling and looking better (3). Because increased physical activity levels can enhance individual physical working capacity, there is an increased probability that usual activities of daily living will be performed. Those beneficial effects of physical activity have important implications for the health of all Americans, especially the elderly.

The Public Health Service has proposed 11 physical fitness and exercise objectives to help Americans achieve those health-related benefits (7). Two of the 11 objectives specifically seek to identify the proportion of American adults engaged in regular physical activity. Those objectives are

By 1990, the proportion of adults 18-65 years old participating regularly in vigorous physical exercise should be greater than 60 percent; and

By 1990, 50 percent of adults 65 years and older should be engaged in appropriate physical activity, for example, walking, swimming, or other aerobic activity (7).

Those two objectives differ in the projected proportions for regular physical activity. This difference allows for the well-documented decline in physical activity with age (8, 9, 10). The objectives also differ in the use of the terms "regularly," "vigorous" and "appropriate." For those objectives "appropriate physical activity" was defined as "exercise which involves large muscle groups in dynamic movement for periods of 20 minutes or longer, three or more days per week, and which is performed at an intensity of 60 percent or greater of an individual's cardiorespiratory capacity." (7) This definition of appropriate physical activity is similar to that for regular, vigorous physical activity. This type of physical activity is set to develop and maintain maximal cardiorespiratory capacity—a factor believed to be cardioprotective (11). The challenge is to identify the 60% level of cardiorespiratory capacity, because such capacity is known to vary by age and sex (12, 13, 14).

We used the 1985 National Health Interview Survey, Health Promotion Disease Prevention (NHIS-HPDP) survey data to examine the effect on the prevalence of appropriate physical activity when two different scoring procedures are used to select the 60% level of maximal cardiorespiratory capacity.

Methods

The NHIS-HPDP survey was conducted in 1985 to establish the prevalence of health behaviors primarily for tracking progress on the 1990 objectives (15). A detailed account of the sample selection and survey administration procedures has been published (15); however, a summary is provided herein.

The NHIS-HPDP survey was based on a probability sample of the noninstitutionalized civilian population of the United States. Trained interviewers administered a questionnaire during a personal household interview according to an established protocol, thereby ensuring data completeness and quality control. Persons 18 years of age and older were randomly selected from a household by using a complex multistage area probability design. The first stage provides for the sampling of 200 out of approximately 1900 primary sampling units (PSU). A total of 40 households was allotted to each segment within a given PSU. A systematic sample of eight households was drawn from those 40 households. In total, 33,630 individual questionnaires were completed, yielding about a 90% response rate (15).

The NHIS-HPDP survey data provided the following elements required to estimate appropriate physical activity: type of physical activity done in the past 2 weeks, frequency of the activity, duration of each session in hours and minutes, and the degree of change in heart rate or breathing while performing that activity. Age and sex information are also available on the survey.

We used two procedures to establish the 60% level of cardiorespiratory capacity. One procedure uses 6.0 METS as the criterion level as previously proposed by Taylor and colleagues (16). One MET is the value of resting oxygen consumption relative to total body weight and is generally ascribed the value of 3.5 milliliters of oxygen per kilogram body mass per minute. Six METS would be equivalent to six times the resting level (17). An intensity of 6.0 METS is roughly 60% of the individual cardiorespiratory capacity of 35 to 57 year-old-men of Taylor's population. The 6.0 MET level was appropriate for men of those ages. Unfortunately, such a code would be too lenient for younger men and women and too stringent for older people.

The other procedure used to estimate individual maximum cardiorespiratory capacity was derived from one of two sex-specific regression equations proposed by Jones and others (18), using age as a predictor variable. For men we used the formula: Maximum Capacity (METS) = [60 - 0.55 Age (years)] · 3.5^{-1}. For women we used the formula: Maximum Capacity (METS) = [48 - 0.37 Age (years)] · 3.5^{-1}. Those formulae are consistent with the well-known decline in capacity with age (12, 13, 14). The predicted maximum cardiorespiratory capacity was then multiplied by 0.60.

From self-reported heart rate or breathing level data we defined the intensity of the physical activity more precisely, using values reported by Stephens and Craig from the Canada Fitness Survey (20). To determine the final activity intensity (in METS), we selected one of three available codes corresponding to the perceived level of effort associated with usual participation. The perceived effort was either none or small, moderate, or large increases in heart rate or breathing. For example, the activity intensity code for three levels of tennis participation would be 4, 6, and 10 METS, respectively, as the perceived effort increased from none or small to large increases in heart rate or breathing. One intensity code was used for calisthenics or general exercise, golf, swimming or water exercises, skating, and skiing (9).

For an activity to qualify someone to meet the intensity criterion for appropriate physical activity, the activity intensity code had to meet or exceed the 6.0 MET level or the 60% level of the individually established maximal cardiorespiratory capacity found by the age- and sex-specific regression equations. Two or more activities could be combined to meet the requirements of appropriate physical activity. In addition, we categorized each of the reported activities as likely or unlikely to be dynamic and involve large muscle groups when performed by most people (as set forth in the definition of appropriate physical activity). Fifteen activities were considered unlikely to involve rhythmically contracting large muscle groups (9).

We also derived a kilocalorie score by calculating the product of frequency (occasions per week), duration (hours per occasion), and MET intensity level for each activity. Because the MET intensity is also roughly equivalent to one kcal$\cdot$ kg body weight^{-1} $\cdot$ hr^{-1}, the sum of the products becomes kcal $\cdot$ kg^{-1} $\cdot$ wk^{-1}; when divided by seven days per week, it becomes kcal$\cdot$ kg^{-1} $\cdot$ day^{-1}.

A level of $\geq$ 3.0 kcal$\cdot$ kg^{-1} $\cdot$ day^{-1} has been used by Schoenborn to describe the prevalence of the "very active" in the NHIS-HPDP data (10). However, this level is not synonymous with appropriate physical activity. To evaluate this difference the kilocalorie score was later compared with the proportion of persons performing appropriate physical activity.

Results

The dotted line of Figure 1 illustrates the proportion of men meeting the criteria for appropriate physical activity when the intensity criterion is set at $\geq$ 6.0 METS. The proportion performing appropriate physical activity decreased from 18% for 18- to 29-year-old men to 0.4% for those men aged 75 years and older. A similar trend exists for women as noted by the dotted line of Figure 2--the proportion decreasing from 11% for 18- to 29-year-old women to 0.4% for those women aged 75 years and older.

A different trend is seen for men and women when the intensity criterion is calculated relative to the sex- and age-specific regression equations previously proposed. The solid line of Figure 1 illustrates a U-shaped curve for the proportion of men performing appropriate physical activity when the individual maximal cardiorespiratory capacity was estimated. The proportion decreased from 10% for the 18- to 29-year-old men to 5% for the 45- to 64-year-old men, and thereafter increased to 17% for those men aged 75 years or older. For women, the proportion meeting the criteria for appropriate physical activity decreased from 9% for those women aged 18 to 29 years to 5% for the 45- to 64-year-old women and remained at 6% for those greater than 65 years of age.

We conducted a separate analysis to reveal the types of activities done by those persons who performed either appropriate physical activity or who expended $\geq$ 3.0 kcal$\cdot$ kg^{-1} $\cdot$ day^{-1}. Table 1 reveals the average minutes per day spent in selected types of physical activity by men and women meeting the criteria for appropriate physical activity according to five age groups. As the age increased from 18 years to 75 or more years, conditioning as well as team and racket sports and all other activities declined from about 46 min per day to less than 6 min per day. Time spent walking increased from 13.5 min per day to 38.1 min per day and time spent in lawn and garden/home repair activities varied between 4.9 and 10.0 min per day for the same age range.

Table 2 presents the average minutes per day spent in similar types of physical activity by men and women performing $\geq$ 3.0 kcal$\cdot$ kg^{-1} $\cdot$ day^{-1} of physical activity according to five age groups. As the age increased from 18 years to 75 years or more, conditioning and team and racket sports substantially declined from about 31.0 to 41.0 min per day to about 7.5 min per day. Average time spent walking increased over twofold, from 20.2 min per day to 48.9 min per day, whereas time spent in lawn and garden/home repair activities increased markedly from 8.2 to 33.2 min per day from ages 18 years to 75 years and older.

Discussion

Two of the 11 1990 physical fitness and exercise objectives are concerned with the estimated prevalence of physical activity participation in American adults aged 18 years to 65 years and older (7). The definition of appropriate physical activity requires that a level of 60% of maximal cardiorespiratory capacity be met or exceeded for three or more times per week and for 20 or more minutes per occasion. Because maximal capacity varies by age and sex, we anticipated divergent results when two different levels were used for the 60% level of maximal cardiorespiratory capacity.

For example, when a single criterion level of 6.0 METS was used, the proportion of men and women performing appropriate physical activity decreased with increasing age as evidenced in Figures 1 and 2. This decrease illustrates the fact that younger persons having a much higher capacity can easily exceed that criterion level, whereas those aged 75 years or older would have to be physically active at a level greater than their maximum (14).

We observed different results when the 60% criterion level was individually estimated by age- and sex-regression equations. Figures 1 and 2 illustrate that the proportion of men and women performing appropriate physical activity, when using individually estimated maximal capacity, demonstrated a U-shaped curve for men and a slightly declining trend followed by a plateau for women. In fact, those men older than 65 years of age actually did better than any of the younger men. The lowest amount of appropriate physical activity noted for middle-aged men and the plateau reached by middle-aged women is similar to results reported by Stephens (20).

A separate analysis was done to evaluate the contribution of varying types of physical activity for attaining appropriate physical activity. For example, Table 1 reveals that persons older than 65 years spent much less time, on average, in conditioning activities, much more time in walking, and about the same amount of time in lawn and garden/home repair activities as persons younger than 65 years.

A different trend exists when one examines the time spent in the same activity categories by those men and women expending an average of $\geq$ 3.0 kcal$\cdot$ kg^{-1} $\cdot$ day^{-1}. As shown in Table 5, time spent in conditioning activities declines with advancing age, whereas time spent in walking increases. Time spent in team and racket sports and all other activities decline with increasing age above 18 years. However, time spent in lawn and garden/home repair activities increases with advancing age, except for a slight decline in those aged 75 or older.

Tables 1 and 2 also illustrate that compared with those who expend $\geq$ 3.0 kcal$\cdot$ kg^{-1} $\cdot$ day^{-1}, those performing appropriate physical activity are more likely to perform conditioning activities, but less likely to be engaged in lawn and garden/home repair activities.

Lawn and garden/home repair activities are good for caloric expenditure when those activities are sustained. However, they are usually not intense enough to qualify someone as performing appropriate physical activity. Folsom et al., using a similar physical activity survey, found that many lawn and garden/home repair activities tended to have poor test-retest reliability than other activities (21). Hence, self-reported lawn and garden/home repair participation in the NHIS-HPDP may be subject to similar problems as well. For the elderly, walking is an activity that is high enough and occurs frequently enough to help one qualify for appropriate physical activity.

LaPorte et al. (22) have suggested that many intercorrelated dimensions of physical activity may be associated with different aspects of health. The activities reported by persons who perform appropriate physical activity and persons expending $\geq$ 3.0 kcal$\cdot$ kg^{-1} $\cdot$ day^{-1} reflect different types of physical activity and may also represent the intercorrelation of different physical activity dimensions. For example, those persons performing appropriate physical activity are committed to improving or maintaining maximal cardiorespiratory capacity, whereas those persons expending $\geq$ 3.0 kcal$\cdot$ kg^{-1} $\cdot$ day^{-1} are merely committed to large energy expenditure, whether or not it improves cardiorespiratory fitness.

Although the 1990 objectives seem useful, they are not necessarily the final answer to all physical activity issues. We do not wish to suggest that only regular and intensive participation is important for promoting the many benefits of physical activity. In fact, regular but less intensive activity participation is also beneficial, and is more likely achieved by those who were previously sedentary or irregularly active (23). As such, we have already extended our scoring procedure to quantify those who perform both intensive, and less intensive, regular activity to measure both physical activity patterns that may enhance health (9).

We have assumed that the regression equations for estimating maximal cardiorespiratory capacity represent the general population. We found some evidence that the formula for men is adequate (24). Regardless, formulae accounting for the overall population decline in maximal capacity are useful to apply in large study populations as we have done, given that the 6.0 MET level is inappropriate. In addition, we, as well as others, have assumed that the intensity codes are valid for the elderly. More research on the metabolic cost of physical activities performed at varying levels of effort and by different population subgroups can help determine the suitability of the existing intensity codes.

Summary

We have demonstrated that estimating the proportion of adults performing appropriate physical activity is more equitably derived when a 60% criterion level based on individually estimated maximal cardiorespiratory capacity is used, rather than simply choosing a 6.0 MET level. The use of the 60% criterion level is especially important for the elderly who tend to have reduced functional capacity associated with advancing age (12, 13, 14).

Other investigators have found that the elderly actually spend less time in physical activity participation than younger persons (8, 9, 10). However, the elderly tend to do at least as well as, and sometimes better than, middle-aged adults in performing appropriate physical activity as set for the 1990 objectives.

Although a kilocalorie summary index of physical activity is useful as a measure of total energy expenditure throughout the week, it does not necessarily identify a commitment to regular physical activity. Further, the kilocalorie score may be inadequate because of the large contribution of lawn and garden/home repair participation that tends to have poorer reliability than other activities. We therefore propose our scoring procedure as a sound approach to measure appropriate physical activity as defined by the 1990 objectives, for the elderly as well as for other age groups.

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Figure 1. Percent of Men Performing Appropriate Physical Activity According to Intensity Criterion, by Age

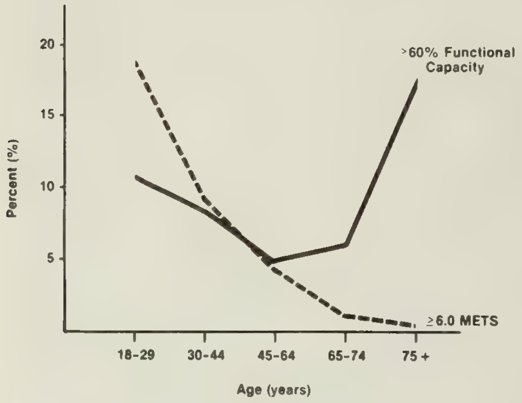


Figure 2. Percent of Women Performing Appropriate Physical Activity According to Intensity Criterion, by Age

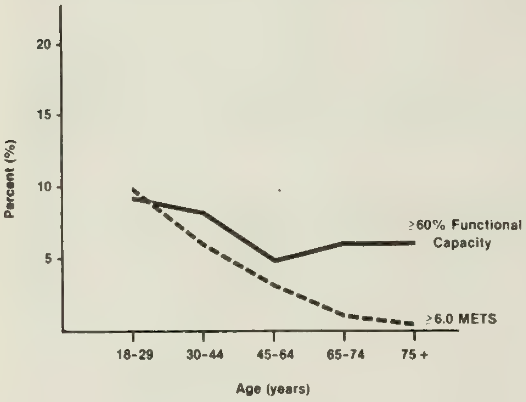


Table 1 Average minutes per day spent by persons performing appropriate physical activity by age and activity type

	Age Groups				
Activity Type(s)	18-29	30-44	45-64	65-74	75+
Conditioning*	45.5	34.1	30.2	14.5	5.5
Walking	13.5	11.7	18.2	28.8	38.1
Lawn & Garden/Home Repair	4.9	8.6	9.4	10.0	4.9
Team & Racket Sport, and all Other Activities	46.3	23.9	16.7	8.3	0.8
Total Minutes	110.2	78.3	74.5	61.6	49.3

*Includes jogging/running, aerobics/aerobic dancing, calisthenics, cycling, swimming, and skating.

Table 2 Average minutes per day spent by persons expending $\geq$ 3.0 kcal$\cdot$ kg^{-1} $\cdot$ day^{-1} by age and activity type

	Age Groups				
Activity Type(s)	18-29	30-44	45-64	65-74	75+
Conditioning	30.6	22.0	15.8	10.2	7.2
Walking	20.2	21.2	30.8	37.5	48.9
Lawn & Garden/Home Repair	8.2	17.9	33.1	47.3	33.2
Team & Racket Sports, and all Other Activities	41.0	25.7	17.9	13.4	7.5
Total Minutes	100.0	86.8	97.6	108.4	96.8

Session B

Panel on Data for Public Policy: Different Perspectives

DATA FOR AN AGING POPULATION

URBANA CHAMPAIGN

Public Policy Issues - Perspective from the National Committee on Vital and Health Statistics

Ronald G. Blankenbaker, M.D.

Introduction

The National Committee on Vital and Health Statistics (NCVHS) has a long-standing interest in data related to our aging population, and hopes to play an important part in this arena for many years to come. As a means of introduction, it would seem appropriate to give you a brief history of the development of the National Committee along with an explanation of its current organizational structure.

In 1948, the first World Health Assembly recommended that each member country should designate a statistical body which would serve as a link to the World Health Organization, and would coordinate vital and health statistics' activities within the member country. For this reason, the NCVHS was created in 1948 and has functioned as such since that time.

Originally, the NCVHS was primarily a technically-oriented Committee composed of 10-12 subcommittees. Each of the subcommittees was composed of seven experts in a specified technical area who were not necessarily members of the NCVHS. The primary role was to study very technical, statistical questions.

In 1974, Public Law 93-353 (Public Health Service Act) broadened the role of the NCVHS to include essentially all matters regarding vital and health statistics whether they be technical or otherwise. This law also expanded the membership from 12 members to 15 with a turnover of 5 each year, and made the Committee advisory to the Secretary of the Department of Health and Human Services (DHHS). The Committee continued to function in a relatively technical manner until budgetary constraints made it difficult to provide the support necessary for a multitude of technical subcommittees.

In 1982, a new charter was developed by DHHS which must be reissued every two years by the Department. This charter requires an annual report to the Secretary of DHHS (through the Assistant Secretary for Health). In addition, the interest and expertise of those selected to be members of the Committee has been broadened over the past five years to include individuals interested in public policy, clinical medicine and nursing, and hospital administration, along with a variety of other health and statistically-related areas. These broad responsibilities have been carried out with the excellent support of the staff of the National Center for Health Statistics (NCHS), as well as that provided by a variety of other agencies, especially, the Health Care Financing Administration (HCFA).

Currently, the Committee has determined that its function is to monitor, as best as it can, the full spectrum of issues regarding vital and health statistics. This includes the evaluation of available data and advice on the development of new data necessary for the creation of effective public policy.

To accomplish these broad mandates, the NCVHS has developed an ongoing and dynamic two-year work plan which encourages one to two-year formal reports from each of its areas of activity. The Committee receives regular, brief, but informative updates on broad statistical issues from a variety of public and private agencies, as well as individuals. In addition, individual members of the Committee have been assigned to special areas of interest to monitor and to provide regular reports to the Committee. Data related to the aging population is an example of one of these areas.

To deal with those areas of key interest, the Committee functions through formal subcommittees composed of members of the parent National Committee, as well as informal work groups, which give regular reports to the main committee. In addition, the National Committee has regular meetings and correspondence with appropriate members of the various agencies and the Secretary and his key staff.

Data Needs for Public Policymakers

Today, we are experiencing an "information" explosion. The current escalation of data collection, analysis, and processing capabilities will not plateau or slow down but will rise exponentially in a previously unparalleled manner. Consequently, the information at hand today was clearly unexpected yesterday and that of tomorrow will have a dramatic impact on how we deliver health care. The system cannot adequately prepare itself without innovative insight and direction.

In the development of modern health policy, it is indeed unfortunate that policymakers have allowed the mechanisms to become arbitrary, haphazard, and all too often, oriented toward interest pressures which frequently represent a small minority of the affected public. The result is the creation of many public policies that are chaotic, illogical, unreasonable, and next to impossible to defend and/or regulate by honest and conscientious officials. The key difficulty with modern policy development is the lack of appropriate information (data), inappropriate analysis and interpretation of this information (regardless of whether the data are accurate or not), and/or inadequate development of solutions to the assumed problems. In many cases, the difficulty is not a lack of data but an inability to assimilate the volumes of information that are being provided to busy policymakers.

The modern health policymaker, to be effective, must have at hand a complex information system that delivers concise, unbiased data on a timely basis. Secondly, a system is needed to assess the importance of this information, and to place its elements into appropriate priorities. Thirdly, a mechanism must be developed to turn this intelligence into effective policies with appropriate alternatives for the policymaker to assess. Last, but probably most importantly, a continuous evaluation and reevaluation process is necessary to assure that policies are modified and/or changed as the situation warrants.

Fortunately, the future has some brightness regarding health policy and planning. Washington is beginning to recognize that quick-fix approaches to poorly understood health issues have failed miserably. Examples of some current positive trends are: The Surgeon General's Report: Healthy People; the development of Objectives for the Nation, 1990 and the evaluation of the progress toward reaching them; the AMA's Health Agenda for the American People which provides an analysis of current health issues and recommendations by a cross-section of health professional organizations; and the Interagency Forum on Aging-Related Statistics.

Of most importance in the current evaluation of policy development is the changing relationships between State and Federal responsibilities. Greater cooperation is developing between State and Federal health organizations although much is yet to be done. The worth of State and national cooperative policies and plans that are not created in a vacuum is invaluable and absolutely essential in the creation of a cost-efficient health system that is expected to provide inexpensive, quality care. Hopefully, this trend toward State/Federal cooperation will continue. However, none of these activities replaces the need for better cooperation and coordination at the national level especially among Federal agencies. Much must be done to decrease inefficiencies, duplication of effort and turf battles.

The Aging Population

While the individual statistical systems with which the Committee works are of importance to the understanding of the health of the aging, in 1985 the Committee determined that the aging population was an area in which it wished to place special attention. We have one individual on the Committee assigned to monitor activities in this area and to serve as liaison to the multiple departmental groups involved in major data collection and use of data on the elderly.

Currently, we are monitoring activities of the Interagency Forum on Aging-Related Statistics, the DHHS' efforts for catastrophic illness expenses, the NCHS' data on older persons, and international endeavors regarding statistics on the aging. We will also monitor other such efforts as they may develop.

As we monitor and collect information regarding the aging population, the National Committee will determine areas of special need or interest, and from that create work groups or subcommittees as necessary. For example, we have a subcommittee on long-term care data to assess the adequacy of information available pertaining to long-term care policy issues. It is obvious at this point as mentioned multiple times during this meeting, that there is a great need for cooperation and coordination among the many organizations and agencies that currently collect data regarding this population. The National Committee would hope to be involved in these endeavors and will help wherever it can to improve these relationships.

DATA FOR PUBLIC POLICY USE

Marilyn Moon, Public Policy Institute, AARP

Availability of new and relatively current information on the health and income of older Americans has created important opportunities for using data in decision making. But with that opportunity also comes considerable obligations for use of these data sets. My comments today pertain both to how these rich new data sources might be used and what changes I would like to see in their application to policy making.

My perspective on this subject and my commitment to enhancing informed decision-making led me to go to the American Association of Retired Persons to serve as the first director of the Public Policy Institute--an analysis unit in the Association's Legislative division. Like a number of other associations in Washington and elsewhere, AARP has recognized the need to make informed policy choices and to back such policy proposals with legitimate arguments and statistics. While some of us have been attracted to such positions by a perceived weaker commitment to research in the public sector, these new policy groups also will, I believe, hold their own in generating new policy analysis and in using data such as that being discussed at this conference. But we are likely to be different users than traditional academic researchers; our needs require the most current data possible, even at the expense of some of the richness of detail of data.

The Data's Usefulness

Microdata can indeed be very useful for developing and evaluating policy in at least three ways:

1. Careful analysis can help avoid misconceptions that often arise when policymakers rely too heavily on anecodotal evidence. We often think we know certain truths; for example it is often argued that poverty among elderly widows in mostly a problem of the very old. But while it is certainly true that such women may be in dire financial straites, young widows face about the same risk of being poor as do the oldest of the old. In this instance, a detailed look at poverty statistics for widows grouped by age would avoid an inappropriate stereotype and perhaps misguided policies restricted to the very old.

2. Research using microdata should enable us to target action where it is most needed. In a world of scarce resources, why make policy that is not needed or too broad or too narrow? Data can be used as a check to determine what the likely impact of various proposals will be. For example, if we wish to design a policy to offer protection against prescription drug costs for older Americans, it is extremely important to know what the distribution of drug use is and even what drugs are most heavily used by the elderly.

3. Finally, we need to use data to evaluate whether ongoing programs are operating as expected. Too often policymakers lose interest in legislation once it is passed. But we should use data and analysis to determine whether programs continue to be effective in meeting their intended goals. Moreover, do unintended consequences arise that ought to be considered? A good example of such evaluative activity is examination of the Medicare hospital DRG system. Does it control costs? Does it place patients at additional risk of poor quality care? These vital areas ought to be of interest for future legislative decisions. In this case, the system was introduced with little prior study of its effect on the elderly. An ongoing evaluation is thus even more critical.

Essential Data Gaps

Many policy areas remain under-researched --often because of a lack of data or more correctly, often a lack of current data. In the health area in particular, events have changed so rapidly in the 1980s that it becomes difficult to extrapolate from surveys and program data that are even two or three years old. For example, it has until very recently been impossiple to track the impact of the 1983 legislation that gave us the Medicare DRG system. Data from the Health Care Financing Administration is seldom very current. In HCFA's defense, it is important to recognize that the information being used has primarily been developed for paying bills and managing the program. But the federal government is now paying out over $70 billion dollars a year and ought to know more about what it gets for its money. The research budget for HCFA amounts to less than .03 percent of its total budget. No private business would (or should) stand for being so ill-informed.

Rather than chronicling at length specific areas where we are missing income, consumption and health data, I would like to mention two specific gaps. The first is the neglect of state specific information. We hear a great deal of talk about how critical are state initiatives in health, income support, long term care and social services, but we do not then follow through with the same kind of attention to data needs at that level. Some efforts are underway to redress this through program and administrative data at the state and local levels, but we have failed at the national level to expand sample sizes sufficiently to be able to disaggregate our large data bases by state. Over time it will be very important to judge whether Alabama is doing as good a job as Kansas in servicing the needs of our older citizens. But as of now, the decennial census is the only source of information that allows such comparisons. And 1979 data are often not very helpful in addressing 1987 policy questions.

The second critical gap I see in policy relevant research does not arise from deficiency in the data, but rather from the outlook of many researchers--particularly those serving the Congress and the Administration. Much of our official policy analysis focuses on assessing the government costs of programs, giving a distorted picture of whether costs have been saved or increased by particular policy changes. Only such a narrow view would result in the claim that shifting higher costs of medical care off onto Medicare beneficiaries was a "savings." We ought instead to look at the full costs and benefits of policies to society as a whole and not just to the impacts on the federal Treasury. The enormous concerns over the federal deficits can lead to bad policy if the analysis is framed too narrowly.

Conclusion

The bottom line is that researchers and data collectors can make an important difference in promoting better decision making by public administrators and legislators. We are still faced with problems that arise from poor analyses and distortions of the information. Nonetheless, I would much prefer to think of our lawmakers debating the merits of studies with opposing conclusions than comparing the anecdotal evidence from a handful of constituents. The challenge to the research community is to make policy makers aware of the value of research and then to do it in relevant and timely manner.

PANEL ON DATA FOR PUBLIC POLICY: DIFFERENT PERSPECTIVES

Other Panelists:

G. Lawrence Atkins
U.S. Senate Special Committee on Aging

David J. Butler
Health Care Financing Administration

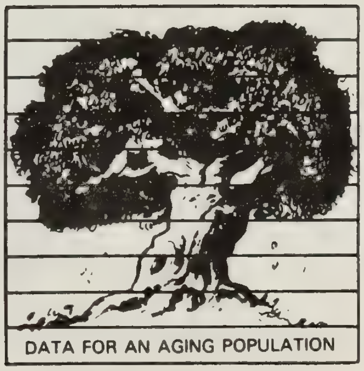
John M. Cornman
Gerontological Society of America

Anthony Knettel
U.S. House of Representatives Select Committee on Aging

(Not available for publication)

Session C

Data Bases and Resources: National Center for Health Statistics, U.S. Bureau of the Census, and the National Institute on Aging



DATA FOR AN AGING POPULATION

THE LONGITUDINAL STUDY OF AGING: THE 1986 REINTERVIEW PUBLIC-USE FILE

Mary Grace Kovar, National Center for Health Statistics

The Longitudinal Study of Aging, a collaborative project of the National Center for Health Statistics and the National Institute on Aging, is designed to measure change among older Americans. In particular, it is designed to measure change in functioning and in living arrangements.

The Longitudinal Study of Aging (LSOA) is a complicated project that will not be completed until the early 1990's (Figure 1). Based on the Supplement on Aging (SOA) to the 1984 National Health Interview Survey, it will include matches with the National Death Index for all 16,000 participants who provided the matching information and gave permission for the match, reinterviews with selected subsamples of the SOA participants, and matching with the Medicare Part A files of the Health Care Financing Administration.

The SOA public-use file was released in December of 1986. It has been fully documented in Vital and Health Statistics Series 1 Number 21, which is free to everyone purchasing either SOA or LSOA files from NCHS and can be purchased by anyone else from the Government Printing Office.

Today it is my privilege to announce the release of the first public-use file from the LSOA. The Longitudinal Study of Aging 1986 Reinterview Public-Use File is now available.

It contains: the 1986 Reinterview data; selected data from the 1984 National Health Interview Survey Core questionnaire; Health Insurance Supplement; Supplement on Aging (if I have failed to include something that an analyst desires from any of those files, the ability to link to all NHIS 1984 files has been maintained); and data from the 1984-1985 National Death Index match for the 5,151 people age 70 or over in 1984 who were in the 1986 LSOA Reinterview sample.

It is a well-documented file. The tape documentation is 284 pages long, not including the introduction and the appendices. The introduction is a description of the study, the interview procedures, response rates, and some statistical considerations for the analyst. The documentation includes sample counts for all categorical variables on the 1984 SOA and the 1986 LSOA reinterview.

A readable version of the 1986 reinterview questionnaire is included in the documentation. I stress "readable" because the 1986 LSOA Reinterview was a Computer-Assisted Telephone Interview.

The 1986 LSOA Reinterview sample has been post-stratified to U. S. Bureau of the Census population estimates to make the weighted estimates from the sample representative of the United States population of people age 70 and over living in communities in 1984. The weights are on the file.

Also, because NCHS is developing software to make the analysis of data from surveys with complex sample designs easier for the user, software that should be available in 1988, a weight that is not post-stratified is included on the file so that users can take advantage of the new software when it is released.

Because variance estimation programs that incorporate complex sample designs assume that there is at least one sample person in each pseudo-PSU, and since we knew from the SOA that there would be some PSUs without a sample person and many with only a few, the pseudo-PSUs were combined to produce an expected 10-sample persons in each, while preserving essential features of the NHIS sample such as the ability to make regional estimates. These new pseudo-PSUs and the strata are also on the file.

The 1986 LSOA sample of people age 70 and over was designed to select everyone age 80 and over in the 1984 SOA sample, all black participants, a half sample of all other participants age 70-79, and everyone age 70 and over living with someone who was selected (Figure 2). The family members were included to facilitate family analysis—a change in a spouse's health status might influence the movement of a couple. Because the LSOA Reinterview sample was drawn before the final SOA file was ready, we did not achieve perfection—five people age 80 and over and three black people were not selected.

Response rates were high (Figure 3). All but 417 of the 5,151 people were located, and if they were still living, their current functional status and place of residence was ascertained. We anticipate that some of the 417 people who were not located have died, but there is no one to report for them. We may find them on the repeat 1985 or on the 1986 National Death Index match.

Those who were not located were much more likely than others to be living alone and were much less likely to have a telephone (Figure 4). They were also somewhat less likely to be men (which is not surprising because aging men seldom live alone), to be white (again not surprising because black people are less likely to have telephones), and to be without any reported difficulty with Activities of Daily Living in 1984.

I strongly recommend that anyone using this, or any other longitudinal study of older people, keep such potentials for bias in mind when analyzing the data.

The price of the file when ordered from the Computer and Systems Programming Branch, Division of Health Interview Statistics, National Center for Health Statistics, is $200. Please specify whether a 1600 BPI or 6250 BPI tape is needed. The purchaser will receive the full documentation and all NCHS reports, manuals, etc. that document the study.

People at institutions that are members of the Inter-University Consortium can obtain the tapes through the National Archive of Computerized Data on Aging. There is no cost to member institutions. NCHS reports must be purchased separately from the Government Printing Office.

People at schools of public health that are supported in their data-tape acquisition by NCHS can obtain the tape through the contact person at the school.

Finally, the National Institute on Aging is receptive to grants for analyses of this and future waves of data from the LSOA. The address is: Building 31, Room 4-C-32, National Institutes of Health, Bethesda MD 20892.

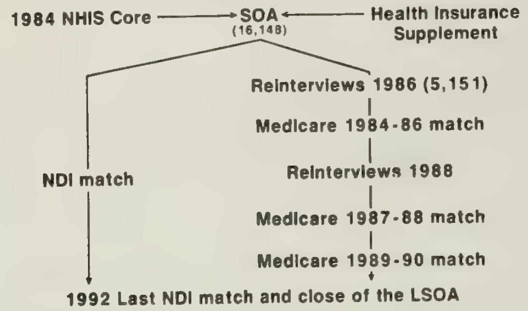
The analytic potentials are exciting. The first national estimates from the LSOA are in another paper in these Proceedings. They merely suggest the analytic potential of the data from this study.

Reference

1. National Center for Health Statistics, J. Fitti and M. G. Kovar: The Supplement on Aging to the 1984 National Health Interview Survey. Vital and Health Statistics. Series 1, No. 21. DHHS Pub. No. (PHS) 87-1323. Public Health Service. Washington. U.S. Government Printing Office. June 1987.

Figure 1

The Longitudinal Study of Aging



SOURCE: NCHS, Longitudinal Study of Aging, 1986

Figure 2

LSOA 1986 reinterview sample

	SOA	LSOA	
	Number	Number	Percent
Total	7,541	5,151	68.3
Age in 1984			
70-79	5,446	3,061	56.2
80 and over	2,095	2,090	99.8
Race			
White	6,891	4,535	65.8
All other	650	616	94.8
Black	563	560	99.5
Other	87	56	64.4

SOURCE: NCHS, Longitudinal Study of Aging, 1986

Figure 3

Response to the 1986 LSOA reinterview

	SOA	
	Number	Percent
Total	5,151	100.0
Status known	4,734	91.9
Alive	4,130	80.2
Live alone	1,597	31.0
Live with others	2,323	45.1
Live in institution	192	3.7
Not reported	18	0.3
Deceased	604	11.7
Status unknown	417	8.1

NOTE: Some with status unknown will be located through NDI matches.
SOURCE: NCHS, Longitudinal Study of Aging, 1986

Figure 4

Response status of 1986 LSOA reinterview sample by 1984 characteristics

	Total	Response status known			Unknown
		Total	Deceased	Alive	
			Number		
Total	5,151	4,734	604	4,130	417
			Percent		
Total	100.0	100.0	100.0	100.0	100.0
Who were:					
Age 80 and over	40.6	40.5	59.9	37.7	41.5
Male	36.0	36.3	48.0	34.6	33.1
White	88.0	88.3	90.2	88.1	84.6
Lived alone	38.9	36.6	30.3	37.5	45.6
Had telephone	96.8	97.5	96.9	97.6	88.7
Without ADL difficulty	71.2	70.9	48.8	74.1	67.9

SOURCE: NCHS, Longitudinal Study of Aging, 1986

THE NATIONAL NURSING HOME SURVEY

Evelyn S. Mathis, National Center for Health Statistics

To continue this review of data sources, my role here today is to provide an overview and brief description of the National Nursing Home Survey (NNHS), one of eleven data systems at the National Center for Health Statistics collecting information on various aspects of health in this country. However, prior to describing the NNHS, I would like to mention two other surveys that can provide data on the aging population.

The first of these is the National Hospital Discharge Survey. The National Hospital Discharge Survey is based on a sample of discharges from non-Federal, short-stay hospitals in the 50 States and the District of Columbia. This survey can provide information on lengths of stay, diagnoses, surgical operations, and patterns of use of hospitals for care. Data collection has been continuous since 1964, thus, it is possible to utilize it for certain trend analysis. The data are published in Advancedata and Series 13 reports. Public use tapes are available for all years beginning with 1970.

The second survey that I would like to mention is the National Ambulatory Medical Care Survey. This survey is based on a sample of visits to office-based physicians and was most recently conducted in 1985. Prior to 1985 it was conducted annually from 1973 through 1981. In addition to demographic data, this survey provides information about the reason for the visit and the medical diagnosis. Data from this survey are also published in Advancedata and Series 13 reports. Public use tapes are available for all of the survey years.

At this time, I would like to turn your attention to the National Nursing Home Survey which was last conducted in 1985.

The 1985 NNHS was the third in a series of nursing home surveys. The first survey was conducted in 1973 and the second in 1977. These three surveys were preceded by a series of surveys between 1963 and 1969 which were called the resident places surveys. While each of these past surveys emphasized different topics, they all provided some common basic information about nursing homes, as well as about their residents and staff. Thus, these surveys can be used for trend studies.

The sample selected for the 1985 survey consisted of 1,220 nursing and related-care homes. Data were collected by interviewers through a combination of personal interviews and self-enumerations with the use of six components or questionnaires. Information about the facility, (namely, number of beds, type of ownership, certification status, number and kinds of staff, and per diem rates) were collected through a personal interview with the administrator or designee. With the administrator's permission, a questionnaire was sent to the facility's accountant to obtain basic expense and revenue information. Administrators and accountants were also given the option of submitting a recent financial statement in lieu of completing the Expense Questionnaire. A maximum of four registered nurses was sampled to obtain demographic characteristics of registered nurses working in nursing homes; information about their level of education and information related to job retention, salaries, and duties. Through interviews with appropriate nursing staff who were requested to review the medical records, information was collected on a sample of no more than five current residents and six discharges. In addition to basic demographic characteristics about the residents and discharges, data were collected about their medical conditions, impairments, hospitalizations during the nursing home stay, functional limitations, services received, history of nursing home utilization, and sources of payment. A family member or other acquaintant of current residents and discharges were contacted by telephone to obtain data on the resident's health and functioning status during the period preceding the admission and prior episodes of health care -information which generally is not available in the facility's records.

Ninety-three percent of the facilities that were eligible to participate in the survey participated. In addition, questionnaires were completed for 97 percent of the residents; 95 percent of the discharges; 80 percent of the RN's and an Expense Questionnaire was completed for 68 percent of the facilities. As you can see, the response rates were relatively high for most of the components. The results of the 1985 NNHS will be released in Advancedata reports, Series 13 reports, public use computer tapes, and according to individual requests. The price of the public use tape is $175.00; the price for specific requests will depend upon the complexity of the request. Two Advancedata reports have been published; one on the characteristics of nursing homes and the second on the utilization of nursing homes. Other reports are in various stages of preparation.

I realize that this overview has been very brief, please feel free to inquire about the NNHS during this conference and in the future by contacting the Long-Term Care Statistics Branch.

THE SURVEY OF INCOME AND PROGRAM PARTICIPATION: NEW DIMENSIONS IN POLICY DATA

David McMillen, Ph.D.
U.S. Bureau of the Census

(Not available for publication)

INTERFACE BETWEEN RESEARCH INITIATIVES AND DEVELOPMENT OF DATA RESOURCES

Richard M. Suzman, NIA

NATIONAL INSTITUTE ON AGING DATA DEVELOPMENT ACTIVITIES

The National Institute on Aging conducts and supports biomedical, social, and behavioral research and research training focussed on the aging process and the diseases and other special problems and needs of older people. Research supported by the NIA is focused on alleviation or elimination of the physical, psychological, and social problems experienced by many older people.

The Behavioral and Social Research Program, one of three extramural programs at the NIA, has as its primary goal the funding of research by the extramural community. In order to accomplish this mission BSR utilizes grants, cooperative agreements, interagency agreements, and contracts to develop and archive data bases that can be used by extramural grantees. Since I am located within this Program, and am oriented toward developing data for extramural research, I will be concentrating on this Program, and the research initiatives of the Demography and Population Cluster Cluster within the Program.

Much of the initial drive to develop data for extramural scientists has been fueled by our Institute's high priority initiative on the oldest old, those aged 85 and over. This initiative, which is centered in the Demography and Population Epidemiology Cluster within the Extramural Behavioral and Social Research Program, has striven to overcome the absence of high quality data on this special population, especially in the area of change in functional capacity and the ability to live independently.

As the Oldest Old initiative gets underway we are beginning to turn our attention to other areas that relate to our program research initiatives, such as the linkages between health and economic status, current patterns of labor force activity among older individuals and their retirement behavior, forecasting active and disabled life expectancy, etc. As we proceed we are developing matrices of the important research questions by the major surveys to see how well each of the questions are addressed. In this respect we welcome any suggestions from researchers about needed data. I should also strongly emphasize that we welcome research applications that utilize these databases that we are developing. Many applications, at least in my area, are entirely based upon secondary data analysis.

I will first review some of the data collection activities associated with the extramural program, starting with the traditional activities of data archiving and the use of interagency agreements, and ending with some new innovative approaches that use the grant mechanism. I will then briefly list some projects that we are thinking about. Finally I will list some of the data collection activities of the Intramural Epidemiology, Demography and Biometry Program, although the data collected by that program is not immediately available to extramural researchers.

National Archive for Computerized Data on Aging (NACDA)

Through a center grant to the University of Michigan, the NIA supports the National Archive for Computerized Data on Aging (NACDA), which provides survey data on aging to researchers around the world for secondary analyses. Information and a catalogue describing the extensive holdings can be obtained from NACDA. All data files developed as a result of the extramural Interagency Agreements are archived at NACDA. (NACDA Project Officer: Michael Traugott 313/764-5199)

International Database on Aging

This Interagency Agreement provides funds to the Bureau of the Census to develop an International Database on Aging. The Database includes demographic, social, and economic information on foreign populations tabulated by age. A public use data file of the Database has been released to the scientific community and is being archived at the NACDA; and a monograph on the Database, entitled "An Aging World", will be published in 1987. In FY1987, funds were added to the agreement in order to allow the Center for International Research to begin the process of adding disability to the IDBA in collaboration with Dr. Chamie of the UN Statistical Office, and to prepare a Report on Aging in the Developing countries. An advisory panel on the IDBA has recommended that the IDBA be enlarged to include additional countries and additional measures, especially in the area of health status, disability, health care usage, and the family. Funding for these activities is deferred, although the Agency for International Development has agreed to cofund the extension of the database to include additional developing countries. (Census Project Officer: Barbara Torrey)

1980 Census Special Tabulations

This Interagency Agreement provides funds to the Bureau of the Census to prepare special tabulations from the 1980 Census on the older population by five year age intervals up to age 85, and where possible beyond that age. One set of tabulation were run on Summary Tape File Number 5, while another set of tabulations were run on the full Census file. Many of the tabulations were suggested by researchers in the community. The tabulations have been archived at NACDA. (Census Project Officer: Cynthia Taeuber)

Evaluation of the Quality of 1980 Census Data on the Elderly

This Interagency Agreement provides funds to the Bureau of the Census to evaluate the quality of the data on the elderly. The study makes use of the special post Census enumeration survey. (Census Project Officer: Cynthia Taeuber and Greg Spencer)

Annual Census Report on trends in the elderly population

This Interagency Agreement with the Bureau of the Census provides funds to compile and issue an Annual Report on new data and trends in the elderly population. This Report will be coordinated with the Report by the National Center For Health Statistics. (Census Project Officer: Cynthia Taeuber)

SIPP datafile linked health wealth and income file

This Interagency Agreement with the Bureau of the Census provides funds to prepare a special public use linked datafile for the elderly respondents of the health, wealth, and income panels of the Survey of Income and Program Participation (SIPP). The data will be archived at NACDA. (Census Project Officer: Cynthia Taeuber)

Longitudinal Study on Aging - the "LSOA"

This Interagency Agreement with the National Center for Health Statistics provided funds for a sample of respondents from the 1984 Health Interview Survey's Supplement on Aging to be reinterviewed in 1986. The sample consisted of all those over age 80 plus, and one-half of those aged 70-79, plus all minorities over age 70. The reinterview provides information on changes in functional status, residence and living arrangements. The tracking of the mortality experience of the respondents to the Supplement on Aging is done through the National Death Index. The first LSOA data file containing linked records of the 1984 and 1986 respondents plus mortality information can be obtained from NCHS. Subsequent releases will include Medicare data on the respondents. A second followup is being planned for 1988. The data files will be deposited at the National Archive of Computerized Data on Aging. (NCHS Project Officer: Mary Grace Kovar)

Mortality Followback of the 1984 HIS Supplement on Aging Respondents

This Interagency Agreement provides funds to the National Center for Health Statistics to track the mortality experience between 1984 and 1989 of respondents to the 1984 HIS Supplement on Aging. See above (NCHS Project Officer: Mary Grace Kovar)

National Nursing Home Survey Followup

This Interagency agreement provides NCHS funds to recontact the next of kin 1985 resident samples of the NNHS in order to find out the vital and functional status and history of institutionalizations for the 1985 resident, and to develop a linked public use file. Two reinterview waves are planned, and this study is about to go into the field. (NCHS Project Officers: Jennifer Madans and Jacob Feldman)

NCHS Data file on Historical Trends in the Elderly Population

This Interagency Agreement provided funds to the National Center for Health Statistics to prepare a special public use rectangular data file on the elderly population. The data file combines core health items from 1969 to the present from the various NCHS surveys including the NHIS. The data are arranged so that synthetic cohort surveys are possible. Where necessary, data are pooled across years to allow for five-year age breaks. The data files have been deposited at the National Archive of Computerized Data on Aging. (NCHS Project Officer: Mary Grace Kovar)

Health Measures for the Panel Study of Income Dynamics

This Interagency Agreement with the National Science Foundation provides partial funding for the 1986 wave of the PSID (University of Michigan), specifically for the addition of a ten-minute segment to the interview of the heads-of-household and special 25-minute interview of their spouses. The resulting data will be made available to intra- and extra-mural scientists through the National Archive of Computerized Data on Aging.

Annual NCHS Report on trends in the Health of the elderly population

This Interagency Agreement provided funds to the National Center for Health Statistics to compile and issue an Annual Report on new statistical data and health trends in the elderly population. This Report will be coordinated with the comparable Report by the Bureau of the Census. The first Report, "Health Statistics on Older Persons", has just been published. (NCHS Project Officer: Richard Havlik)

The Grant Mechanism and Data Collection

A factor playing an increasing role in NIA's data collection strategy is the scarcity of funds in the NIA contract budget. The budget line for contracts (from which funds for interagency agreements are drawn) is set by Congress, and is currently less than a tenth of the budget line for grants. The grant bulk of NIA's contract budget goes to activities such as the SHEP clinical trials, the animal and cell banks, and the EPESES Studies, leaving only very limited funds available to support the collection of data that will primarily satisfy the research needs of extramural researchers.

This scarcity of funds has lead to a number of actions on our part. We have tended to support low cost but high yield pigggybacking surveys such as the Longitudinal Study on Aging and the National Nursing Home Followup Survey at NCHS in which we can use our leverage to get the data out rapidly to the extramural community. We commissioned a number of position papers on NIA's data collection strategy in demography, epidemiology, and health retirement economics and will be holding a series of advisory group meetings in these areas over the next six months. We are trying to increase collaboration in these areas within NIA as well as Federal Agencies.

The **Federal Forum on Aging-Related Statistics** has become an important avenue to increased cooperation in this arena among Federal agencies. Finally, we tried to bring research grant activity and Federal data collection on the elderly population much closer together.

This last activity has resulted in a much closer integration of the two activities. Let me give you two examples. In one case the comparative international data on the value of non-cash income of older persons that will be collected and computed in a grant to Dr. Timothy Smeeding, now at Vanderbilt University, will also become part of the **International Data Base on Aging**.

In another case, the grant mechanism is allowing an investigator Dr. Kenneth Manton of Duke University to collect a third wave of information in 1988 on the 1984-6 **National Long Term Care Survey**. The Bureau of the Census will collect the data for the 1988 NLTCS under a subcontract from Duke University. Data from Medicare files will also be linked to the data file.

Both of these examples are ultimately hinged on the investigators having a strong commitment to release the data rapidly to the research public - in effect just as soon as they have a reasonably clean file. This release was voluntarily promised by both investigators. Under the grant mechanism we cannot compel any such release -- though I would like to see a rider to all grants that requires the sharing of data by or before first major publication, except under extra ordinary circumstances.

I would like to describe another new partnership effort between extramural researchers and scientists in Federal statistical agencies that is still on the drawing board. The new approach would use the cooperative agreement mechanism (a mechanism halfway between a grant and a contract which uses funds from the budget line for grants) to allow for hypothesis testing followup studies based on Federal Surveys. The cooperative agreement will provide a framework that will allow extramural investigators to develop projects that will follow subsamples from surveys such as NHIS, LSOA, HANES III, SIPP, etc. Most aging research needs longitudinal data, yet most federal surveys are cross-sectional. Many studies need much more detailed information on assessments than are possible in most omnibus surveys. Grantees would develop partnerships with scientists in Federal statistical agencies in order to design hypothesis testing studies that make use of the enormous case finding potential and huge investments of these national surveys. The agencies would collect the data which would be analyzed jointly by both parties. The data, which would always be subject to the usual confidentiality restrictions, would also be archived.

BSR/DPE Proposed Interagency Agreements FY1986 to FY1990

I would now like to list some of the activities that are currently under discussion within the Demography and Population Epidemiology Cluster that I run, along with their current status.

Bureau of the Census:

Tabulations on the Foreign Born Elderly - funding deferred

Economic Trends in the Elderly: linked CPS March Files - funding deferred

Quality of Data on the Oldest Old: Centenarian File - funding deferred

American Housing Survey: longitudinal add on - needs development

SIPP datafile: SSA earnings record and Medicare file linkages - needs solution to access by extramural researchers because such a file could only be accessed through Census.

NCHS:

Health Interview Survey Historical Datafile: extension -- funding deferred

Longitudinal Study on Aging: additional waves FY1988-90 -- awaiting review and funding decision

Department of Labor

A reinterview of the Mature Male Cohort of the National Longitudinal Survey is under discussion.

Social Security Administration:

The Longitudinal Retirement History Survey Re-survey is awaiting Census feasibility clearance. A LRHS reinterview which focussed on the assessment of the physical and cognitive functioning of the LRHS survivors; their current financial status in terms of wealth, income, and consumption; and which would be linked to prior LRHS waves as well as multiple cause mortality data, would be an invaluable resource for extramural investigators. Such a database could serve as a unique resource for investigators interested in many aspects of the NIA's Oldest Old Initiative. The database could, for example, be used to study the dynamics of impoverishment in very old age including spend down, the impact of widowhood, and socioeconomic differentials in morbidity and mortality.

The current status is that we are awaiting the results of a National Academy working group of the Committee on National Statistics that will try to resolve the thorny questions of confidentiality and data access that were caused by the initial collection of the data under Title 13, coupled with the linkage to administrative records. Increasingly as researchers move toward studying the linkages between financial status and other economic variables with health outcomes, they will be forced to rely on linkages to administrative records. Solutions to the inherent obstacles are thus becoming ever more important.

Also under consideration is the development of a new Retirement History Cohort. Given the changes in the family, in the role of women, and in the structure of the American economy, there are many areas where it may no longer be possible to generalize from the old LRHS, and so a new cohort study is needed, but one that is not handicapped by Title 13 constraints in the release of public-use data files.

EPIDEMIOLOGY, DEMOGRAPHY AND BIOMETRY PROGRAM (INTRAMURAL)

Finally I would like to list some of the data collection activities of the intramural EDB Program. Microdata collected by that Program have not yet been made available to the extramural community, although I understand that the NHANES Followup data will soon be archived, and it is the Program's intention to ultimately archive their data.

Followup of National Health and Nutrition Examination Survey I (NHANES I)

The purpose of this project is to design and complete a followup of persons examined in the HANES I to study how factors previously measured relate to the health conditions that have developed since the survey. The three major areas for prediction of outcome are 1) nutrition 2) risk factors for chronic disease and 3) health care utilization. The survey will have a household interview including self-reporting of health conditions, utilization of health services and behavioral and social status plus some physical measurements as blood pressure, height, and weight.

Established Populations for Epidemiologic Studies of the Elderly (EPESE) - Yale University.

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University of Iowa, Harvard University, Duke University

The purpose of this project is to conduct epidemiologic investigations in a community to develop new knowledge concerning the medical and social factors in health and diseases of the aged. Studies are to be completed on problems of pain, vision, hearing, sleep, drug use, constipation, social support and other pertinent areas.

Senile Dementia: Natural History in a Noninstitutionalized Population

The objective of this study is to describe the course of general health and cognitive decline in a group of SDAT victims and controls.

Dementing Illnesses in the Framingham Heart Study

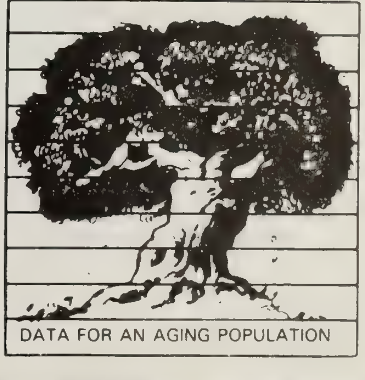
Objective: Current funding supports the continuing neuropsychological and neurological evaluations of all study participants suspected of dementia, the gathering of information related to the diagnosis of dementia from family members of possible cases, data managing, and statistical analysis related to the information generated by these examinations and interviews, and coordination of the dementia/aging disability components of the study.

Survey of the Last Days of Life

The purpose of this project is to collect descriptive data on the last days of life for a community sample of persons age 65 and older whose deaths occurred in a one-year period. In addition to providing specific data on basic events and circumstances surrounding death, the study will provide lifetime prevalence data for a set of conditions related to, but not necessarily causing death. The new knowledge gained from this study will be extremely valuable in relieving the burden of anxiety on family, friends of the dying person, and to providers of care.

Session D

Health, Retirement, and the Ability to Work



DATA FOR AN AGING POPULATION

ARE THE EIGHTIES DIFFERENT? CONTINUITY AND CHANGE IN THE HEALTH OF OLDER PERSONS

Martynas A. Ycas, Social Security Administration[1]

The scope of public policy is strongly constrained by a variety of demographic events -- birth and death, marriage and divorce, work and retirement -- that reflect personal decisions and personal fortunes. While policy is affected by these events, it can rarely control them. Because year-to-year changes in these variables do not matter very much, they are usually left in the background of decision-making, and fluctuations in their levels and rates tend to be followed only by specialists. If changes occur in the same direction over several years, however, the resulting trends can be seen (usually belatedly) to have a major social impact.

The demographic stability of different periods can differ considerably. The Seventies, for example, saw an unprecedented drop in the number of births in 1972 and a similar resurgence in 1977. The number of divorces was 85% higher in 1979 than it had been a decade before. For the first time in history, rural areas began to grow at the expense of urban ones. By 1980, most of these trends -- the "mini Baby Boom", the ever-increasing growth in divorce, the decline of cities -- had entered into conventional wisdom, and we had become accustomed to rapid change along many dimensions. Now that the Eighties are well advanced, it is possible to see that things can be quite different. In many respects this has been a strangely stable decade. The number of births has fluctuated very little, the seemingly irresistible rise in divorce has suddenly levelled off completely, and urban as well as rural areas are growing again.

It may be worthwhile to look again at other trends that were underway during the Seventies to see whether they have, in fact, continued. The focus of this paper is to examine recent developments in one trend, the apparently declining health of older persons in the retirement age range, using data from the National Health Interview Survey (NHIS).

This work had its beginnings in the discussion that surrounded the 1983 Amendments to the Social Security Act. Among the changes now scheduled is a gradual increase in the normal age of retirement. This was felt to be necessary due to three long-standing trends. The first has been a tendency to retire earlier and earlier -- that is, toward decreased labor force participation among older persons. The second has been a steady decline in the mortality rates of older groups and, correspondingly, increases in their life expectancy. The third is a low level of fertility during the past two decades that insures that the number of young replacement workers entering the labor force will be declining for some time to come. The result has been a steady growth in the dependency ratio of workers who pay taxes to older non-workers who collect benefits. Since the Social Security program is funded on a pay-as-you-go basis, this suggests serious implications either for the economic well-being of the elderly who will no longer work or for the long-run tax burden that must be supported by the remaining workers.

Neither birth rates nor death rates can be changed much, at least in the short run, but retirement rates may be more responsive to policy changes. One of the steps taken by the 1983 Amendments to rebalance the dependency ratio was to adjust the incentives for the "young elderly" age group around the age of 65 who are most "at risk" of retirement, in the hopes of encouraging a gradual rise in the prevailing age of withdrawal from the labor force and entry into old-age benefit receipt. The law now schedules gradual increases in the normal retirement age (at which full benefits are payable) from 65 to 67, with various greater reductions in benefits for early retirement and increases for delayed retirement.

These changes raise two questions that bear directly on health: (1) are they fair? and (2) will they work? They were based on an underlying assumption that the recent growth in life expectancy implies better health and increased work capacity at older ages, so that more older persons are now able (if not necessarily eager) to continue working for several years after they choose to retire. Doubts about this assumption were expressed while Congress considered the 1983 Amendments, which in their final form called for further study of this question.

Certainly mortality has been declining steadily for some 20 years, but what are the medical implications of this trend? The epidemiologic transition, completed in the United States around the middle of the century, greatly reduced mortality at younger ages by virtually eliminating deaths due to infectious and parasitic disease (Peery, 1975; Omran, 1977). In the present "Age of Delayed Degenerative Diseases" mortality is not only dominated by chronic, degenerative diseases, but the risk of dying from them is being redistributed to more and more advanced ages (Olshansky and Ault, 1986).

At one extreme, Fries (1980) has proposed that both morbidity and mortality are being compressed near the upper end of the potential lifespan, leading to a rectangularization of the age-mortality curve. Thanks to the prevention or postponement of morbidity due to changes in life style ("increased exercise, lower weight, and growth in personal autonomy and responsibility for health"), an increasing proportion of the potential lifespan is being spent in good health. From this perspective, older persons should generally be finding work less and less demanding.

At the other extreme, Gruenberg (1977) has seen these recent trends as the "failures of success". Mortality has been postponed not by curing or avoiding the underlying causes of death but by curbing the lethality of their side-effects and sequelae, such as pneumonia. The additional persons who are now alive are not healthy; instead the older population contains an increasing proportion of sick persons whose problems can be kept under control at a level of severity short of death.

More complex models of the relations between mortality and morbidity as now being put forth (e.g., Manton, 1982), but unsurprisingly these models are compatible with a wider range of possible changes in work capacity. The meaning and interpretation of mortality trends cannot be derived by armchair reasoning. To see whether older persons can be expected to delay retirement, now or in the future, it is necessary to examine health and activity limitations directly.

The National Health Interview Survey is the obvious source of data for making comparisons over time. It is continuously in the field, interviewing a national sample, uses a wide variety of items that appear to measure health, and has remained fairly constant over time. Major revisions in survey procedure and questionnaire content, which may bias comparisons of years before and after, took place only in 1969 and 1982. Microdata public use tapes are available for years after 1968.

Several studies have already put the NHIS estimates to use in making cross-time comparisons for the health of the older population. Colvez and Blanchet (1981) used published NHIS data to examine disability trends for the age categories 45-64 and 65+ over the interval 1966-1976 (for some variables, only to 1974). Both measures of disability in their analysis (days spent in bed and days of restricted activity) showed an increase over the period, with greater increases in the most severe form (unable to perform usual activity at all). The more severe forms generally increased among older persons; however, men aged 45-64 reported less restriction in major activity, while women aged 65+ reported only insignificant increases.

Verbrugge (1984) has carried out a more extensive analysis along similar lines which tends to confirm and expand these findings. Her time series covers a longer span (1958-1981) but again was constrained to very broad age categories. She found an increase in total restricted activity for older persons, though the trend is much less pronounced for bed disability days. Major-activity limitations have generally been rising among those aged 45-64, but not among the older group. Both "killer" and "nonkiller" chronic diseases tend to be more prevalent and more limiting. Verbrugge attributes this to greater disease awareness due to earlier diagnosis as well as to a reduction or delay in lethal effects, possibly accompanied by earlier accommodation to the effects of disease.

Crimmins (1987) reanalyzed data from the NHIS public use tapes. Her comparisons generally contrast grouped data using a variety of indicator variables for the period 1969-71 (or 1970-71) with data for 1979-81. This produces no indications of improving health for the population aged 55 and above, and some evidence of some deterioration in reported health below age 75 over this interval. Only about half of the reported morbidity was due to causes that can lead to death. More men report that they retired for reasons of health, and retired men (whatever their reasons) appeared less healthy, while the health of working men was unchanged. This suggests that in addition to health changes other factors, such as increasing knowledge and availability of benefit programs, may be causing more men to leave the labor force.

Using a somewhat different approach, Palmore (1986) has derived very different trends over the same period using the same data. To assess changes in the health of the 65+ age group, he focussed not on absolute changes in the level of each health variable, but on changes relative to the rates for the population as a whole. Assuming that the younger population has not been undergoing any substantial deterioration in its average health, only an increase in the relative rates for older persons would indicate worsening health. Apparent declines among the elderly that are matched in other age groups can be attributed to methodological changes in the survey procedure or to period effects for the health indicators.

When relative ratios were calculated for a comparatively large set of health measures (restricted activity days, bed days, injury rate, prevalence of acute conditions, and percentages with visual, severe visual, and hearing impairments), no consistent trend or pattern appeared among the changes in absolute health rates, but the relative health of the elderly improved consistently and substantially. This finding is, of course, dependent on the assumption that health has not deteriorated to some degree across the age spectrum (which would tend to offset apparent changes among the elderly). Still, the upward trend that is reported when relative health is measured is in striking contrast to the results of cross-sectional comparisons of absolute levels of health variables in the NHIS data.

The findings of these studies are therefore somewhat ambiguous. Between the Sixties and Seventies the health of the older population has either fallen or risen, depending on how it is measured. Attempts to link health limitations to their underlying causes does suggest strongly, however, that changes in mortality rates need not be similar to changes in work capacity.

This paper attempts to expand and update the analysis of NHIS data in several ways that will be particularly useful for the study of health and retirement. First, the age range around 65 is separated out as a focus for analysis. Earlier studies have generally followed the well-established practice of breaking the population into age ranges at age 65. For the purposes at hand, this divides the population of greatest interest and dilutes their distinctive characteristics with those of considerably younger and older persons. In the absence of any standard usage, the "retirement age" range is taken here to extend from 55 to 69. Retirement before 55 is quite unusual, and few pension plans permit it. By age 70, work is unusual and earnings no longer offset social security retirement benefits.

Second, both absolute and relative changes in the health variables are examined simultaneously. Rates for the older retirement-age group are calculated as a function of rates in the prime labor-force group aged 25-54, a range in which labor force participation has always been very high for men (because trends in both health and work have often been different for women, they are tabulated separately). This prime age group provides benchmark rates for each health variable, at which substantial interference with the ability to work would not be expected.[2]

Third, data for the first half of the Eighties are used to compare trends in this decade with the trends in the Seventies that have been the subject of earlier studies. The NHIS underwent few changes between the years 1969-1981, but was substantially redesigned in 1982. This raises the problem that apparent changes in the most recent years may result from changing survey methodology rather than changing health, but the years 1982-1985 have now been released in public use form. Even if sharp discontinuities in the data series at 1982 suggest procedural artifacts, four years' worth of recent data can be examined for suggestions of trend.

Fourth, in place of before-and-after comparisons, a large number of points in time are examined to explore whether any changes are simple linear trends or have occurred at different rates in different periods. Seventeen years' data permits a much finer-grained examination of patterns of change. In practice, however, tabulations of annual estimates tended to bury any trends in the data in a mass of minor fluctuations (probably reflecting sampling variability more than actual change from one year to the next). Time series for each variable are presented here in two smoothed-out forms. One groups the 17 years of data into 5 intervals.[3] The other provides a series of moving 3-year averages.

Attachment to the Labor Force The percentages considering work to be their usual (after 1981, "major") activity are shown in Table 1.[4] Since the late Sixties, the proportion of men working near retirement age has fallen from over 70 percent to about 55 percent. Prime-aged men are also less likely to be attached to the labor force, but here the decline is smaller, and so relative rates have fallen. The reduction for older men was rapid in the early Seventies; since then, it has continued quite steadily but much more slowly. Older women have shown almost no change -- just under a third have always reported work as their usual activity -- but the steady growth in participation among prime-aged women has caused the relative percentage near retirement age to decline much more than men's since the mid-Seventies.

Restricted Activity Days While the changes have become gradual, more and more older men have not been working and, presumably, leading less physically demanding lives. It might be expected that fewer of them would report days of restricted activity. This does not seem to be the case (Table 2). All groups, men and women, older and younger, tended to report an increasing number of restricted days over time until the 1982 redesign. Survey changes seem to have led to a substantial drop in the absolute number of days reported, but the relative ratios continued their increasingly gradual climb since the late Seventies.

Activity Limitations Changes in usual activity also qualify any interpretation of the limitation measure. Workers who are unable to perform their major activity for long are likely simply to change their usual activities to a less demanding standard, which limits the percentage who are likely to report severe limitation. Still, among men this variable has shown an interesting pattern. The percentage of prime-aged severely limited men has always been small, but has also tended to increase rather steadily. Older men, who reported higher levels, also had increases until the early Eighties, but then began to report lower levels. Their relative health ratio has therefore improved markedly. In this respect the Eighties are indeed different. Interpretation of the trends for women is more complicated, because the change in 1982 clearly led to sharp increases in reported severe limitation. Here too, however, the relative health of women has improved markedly through the Eighties.

By combining all persons who report a limitation in any activities, even non-major ones, it is possible to construct a measure that should be independent of the observed changes in usual activity (though the advantages of its independence may be offset by a tendency to reflect changes in minor impairments that have no bearing on the ability or desire to work). Men in both age groups were reporting increasing limitation in the early Seventies, but have recently tended to report slightly less (Table 4). The improvement of older men is not keeping pace with that of their prime-aged counterparts, however. After a period of stability in the late Seventies, older women are reporting more limitation, especially compared to prime-aged women.

Bed Days The number of days during the past two weeks spent all or mostly in bed has more promise as an unbiased measure of limitation. While hypochondria on the one hand and urgent demands outside the home on the other are likely to have some tendency to raise or lower the number, this variable might be expected to reflect involuntary, health-related restrictions. In the prime-age population, the number of bed days seems to have peaked in the later Seventies and fallen since (Table 5). In the older age group the number has stayed high for women and actually increased for men, so that a moderate tendency toward improving relative health has reversed sharply. This change in ratios is so abrupt, starting in 1982, that methodological factors may be involved. Note, however, that after the redesign the health of the older group seems to have shown a slight tendency to improve in both absolute and relative terms.

Doctor Visits Like other medical care utilization measures, some of the changes that have appeared over time may reflect changes in the availability of facilities, medical practice, and health care financing rather than changes in health and the need for care. Moreover, this variable shows an obvious abrupt change in 1982 that can be attributed to the redesign (Table 6). All groups showed an increase into the middle Seventies, followed by a decline through 1981. The reported numbers are much higher thereafter, but the relative rates for older men are not much changed. Older women, however, seem to have been seeing doctors disproportionately more during the Eighties.

Episodes of Hospitalization The trends for this variable are quite uniform (Table 7). In the prime age group, numbers peaked around 1974 and have declined ever since. By contrast, the rates stabilized and perhaps fell slightly for older men and women during the late Seventies, but they have increased during this decade.

Number of Hospital Days The average hospital stay has evidently been decreasing. The number of hospital days has been falling for the prime-age group since the early Seventies, while older men and women peaked in mid-decade and have fallen fairly steady (Table 8). Although they clearly are spending less time in hospital, the improvement for older groups has not kept pace and their relative health has been getting worse.

Subjectively Assessed Health Obviously few of these reports of health status are made by persons with medical training, but studies have repeatedly found that they relate significantly to a variety of medical factors -- indeed, health status may be a better single general measure of health than the other variables discussed above (Ware et al., 1978). The NHIS began measuring health status in 1972 with a four-point scale (excellent, good, fair, poor). Because such a large proportion of the responses were at the positive end of the scale, the 1982 redesign included a shift to a five-point scale (excellent, very good, good, fair, poor) to capture more of the variance. Necessarily, a time series must combine all responses ranging from "excellent" to "good" (Table 9). The scale change may have had a slight tendency to increase the percentage whose health was rated as at least "good", but the increases are modest. Such trend as there is toward increasing health in all groups, possibly more rapidly during the Eighties. The relative rates for older women have not quite kept pace, however.

It might be expected that as the percentage in "good" health or better rises, the percentage in "poor" health would fall. This appears to be the case for the prime age groups, but surprisingly, not for the older men and women (Table 10). The change is relatively abrupt in 1982, suggesting scale changes had some effect on the responses of this group. Correspondingly, their relative health deteriorated, though trends in both measures may have begun to improve by mid-decade.

Number of Reported Health Conditions No summary variable of this type is available for the full period, but the early Seventies can be compared with the early Eighties. It is difficult to say whether the distinctly higher levels in recent years reflect changes in prevalence, diagnosis, or survey procedure. The last of these is perhaps the most plausible, since rates seem to have been falling during the earlier period. Relative rates for older men seem essentially unchanged despite the overall rise in reported conditions, but they have recently been worse for older women.

In conclusion, then, what do these measures tell us? Certainly, as earlier studies suggest, morbidity has not been declining in step with mortality for the past two decades. Moreover, Palmore's earlier finding that the health of the elderly is increasing in relative terms is not very well supported. But what of the original question? Are the Eighties different?

The answer depends on what the most recent years are compared with. The first half of this decade, like the late Seventies, seems to have been characterized by often small and inconsistent changes. It would be possible, by picking the right variables to argue that retirement-aged persons have been getting healthier, especially the men. Their withdrawal from the labor force has slowed, they are less likely to be limited in their activities, they are less likely to be hospitalized, and they are more likely to characterize their health as "good" or even better. This is, however, a one-sided selection of the facts. In absolute terms, it can also be argued, using other measures, that the health of men and women is growing worse. In relative terms, this is definitely the case for the preponderance of measures.

When they are compared with the late Sixties and much of the Seventies, however, the Eighties are indeed different. The earlier period was definitely characterized by a marked and usually steady change for the worse on most of the variables examined, and it is mainly the deterioration in this period that was being measured by the earlier NHIS-based studies mentioned above. Like the other demographic trends mentioned at the beginning of this paper, health trends have tended to slow down and become more ambiguous during this decade. In retrospect, the NHIS redesign came at an unfortunate time, because the side-effects of design changes are particularly obtrusive when they are superimposed on relatively small changes in the underlying variables. On the other hand, by the end of the decade we will have a longer and hopefully more interpretable series of numbers based on the new and improved methodology. Until then we will have to remain in doubt.

Notes

[1] The opinions expressed herein are those of the author and do not necessarily reflect the position of the Social Security Administration.

[2] The mean age of the older group remained essentially constant over this period. However, the mean age of the prime group fell rather steadily by about a year. To the extent that age is inversely correlated with health, the relative measures shown here are slightly biased in the direction of declining health for retirement-aged men and women.

[3] Note that both these series are not made up of averages of separate estimates for each year, but are based on pooled individual cases, each weighted by the "annual weight" used to derive estimates for the appropriate year. As seventeen is a prime number, the first set of intervals is necessarily not of equal length, but were divided as suggested by survey revisions and changes in the availability of variables for certain years.

[4] Due to limitations of space, the tables are not printed here. Copies are available on request from the author.

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TRENDS IN SURVIVAL OF PERSONS WITH SEVERE DISABILITY, U.S. 1970-85

MITCHELL P. LAPLANTE, UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

INTRODUCTION

Mortality rates have declined in the U.S. continuously since the late 1960s, largely, but not entirely due to declines in heart and stroke as causes of mortality. Many questions concerning this epoch in epidemiological history remain, but the coincidence of mortality declines with public health care initiatives continuing since the mid-1960s has lead some to conclude that increasingly successful and widespread efforts by the medical community in slowing the rate of chronic disease progression and reducing case fatality rates may be responsible. Indeed, it has been argued that our current experience is sufficiently different from the past, with rapidly improving survival at the oldest old ages, to merit the addition of a fourth phase to the theory of the epidemiologic transition, namely the Age of Delayed Degenerative Diseases (Olshansky and Ault, 1986), or perhaps what could be more appropriately called the "Age of Delayed Death Due to Degenerative Diseases", since the relationship of the onset and duration of disease to these mortality reductions is far from clear. This is reflected in the concern with which the Congress has approached raising the retirement age under social security, to avoid placing an increased burden on the population in ill health at the ages 62-67.

To what extent and in what direction declining mortality is correlated overtime with disability and the quality of life is a question that needs to be explored more fully.

This paper presents some initial attempts in that vein. First, the mortality experience of persons receiving Social Security Disability Insurance (SSDI) is compared to the total population to determine whether there is any indication of differential mortality trends. If mortality rates are falling faster in the SSDI population than for the rest of the population, this may indicate that persons with disabilities are experiencing more rapidly improving survival, and hence, may be living longer with serious disability.

Second, trends over time in the onset and duration of disability are analyzed using data from the National Health Interview Survey. Two periods, 1969-71 and 1979-81, are examined to see if there have been changes in the age of onset and duration of disability. In addition, correlates of disability, in particular restricted activity days, bed disability days, and hospital episodes are compared over time, by degree and duration of disability to address the issue of whether people are more casually adopting the disability role.

RISING DISABILITY IN THE WORKING AGES

The historical rise in disability in the working age population in the U.S. since the late 1950s is hard to reconcile with the argument that disease and disability are being postponed to later ages. This increase has been substantiated through a number of data sources and appears not be a statistical or survey operations artifact (Chirikos, 1986). What is questionable, however, is whether the trend is real from an epidemiological perspective.

For a variety of reasons other than health impairment, people may be more likely over time to adopt the disability role. These include changing awareness of chronic conditions due to increased access to medical services and perhaps improved communication between physicians and patients (Verbrugge, 1984), adoption of more active lifestyles that can elevate short-term disability (Wilson and Drury, 1984), and enhanced monetary benefits through public and private insurance programs (Lando et al., 1982).

Economic reasons are often cited for the dramatic rise in the number of beneficiaries under SSDI. The decade of the 1970s has seen a gradual rise in the number of beneficiaries up to 1978 when the number began to decline and has continued to decline until very recently. It appears that major influences on trends in the SSDI program have been legislative initiatives and changing administration of the program.

The incidence of disability under SSDI rose through the early part of the 1970s, causing fears of insolvency of the DI trust fund and creating some congressional concern.

The incidence of disability under SSDI began to decline in 1976. In 1982, it reached an all-time low and has increased slightly since, but remains below its 1980 level. The reason for the increase after 1982 was public dissatisfaction with legislation requiring stepped up reviews of continuing disability status which lead to revised legislation in 1984.

Beginning in 1972, beneficiaries under SSDI became eligible for Medicare assistance. Due to eligibility rules, however, beneficiaries do not become eligible for Medicare coverage until at least two and one-half years after the onset of a work disability. Nevertheless, if it is the case that mortality declines in the U.S. have been affected by increased access to medical services, we might expect that this major expansion of health care coverage to the working age disabled may have an impact on their mortality experience.

MORTALITY TRENDS UNDER SSDI

Some attention has been drawn to the fact that over the period 1965 to 1981, while the crude death rate for the total population has declined from 9.4 per thousand in 1965 to 8.6 per 1,000 in 1981 for a decrease of 8.5 percent, the crude death rate for disabled workers under SSDI declined by 43 percent, from 84.2 per thousand to 47.7 per thousand over the same period (Kelley, 1984).

This comparison may be misleading, however, since it does not compare rates among similar age groups nor does it control for changes in the age distribution of the two groups. Rather, it is preferable to compare trends in mortality rates for comparably defined age groups.

Mortality rates by age and sex for the SSDI population and the total population are compared in Table 1 for the years 1970 and 1985. Comparisons of the percent change in mortality by age and sex over this period yields a result quite different from the above. In almost all cases, the percent declines in mortality among the SSDI population have been less than for the total population. Thus, the already high ratios of SSDI to total population mortality have actually increased, rather than decreased over this period.

The rate of recovery has increased considerably since 1980 when the Social Security Disability Amendments allowed for more frequent medical review of beneficiaries. In 1982, in fact, the recovery rate exceeded the mortality rate for the first time in the history of the program. Since medical recoveries are in theory more likely among the less severely impaired, it is probable that the increase in recoveries would result in an increase in the mortality rate. Figure 1 shows trends in the crude mortality rates of the SSDI population compared to the total population ages 15-64 plotted on a logarithmic scale. This shows that the percent decline in mortality has been comparable up to about 1982, after which the mortality rate under SSDI increased.

Although very recent increases in recovery rates under SSDI to some extent obscure the picture, it is clear that mortality declines under SSDI have not outpaced declines in the total population, and may have even fallen behind.

TRENDS IN THE ONSET AND DURATION OF DISABILITY

We now examine data from a different source - the National Health Interview Surveys - over the periods 1969-71 and 1979-81. These dates were chosen because they cover the longest expanse in which information was collected on the duration of disability. Three years of data were pooled together to reduce sampling variation.

During these years, questions about limitation in activity were asked of all respondents. Persons who reported being limited were asked for how long they have been limited. In this paper, persons unable to perform their major activity are mainly discussed. Major activity refers to ability to work at a job or business or perform housework. It is an admittedly imperfect measure, since as the survey was designed, it fails to measure ability to work for females whose major activity is housework and there is come ambiguity in how well the concept of ability to perform work or housework apply to the elderly. Nevertheless, the measure is correlated with other indicators of disability such as restricted activity days and bed disability days as well as medical care use.

Information about the duration of limitation permits calculation of the age at onset of disability as well as its incidence. Although the duration of disability is recalled by the respondent, it seems reasonable to expect that recall may not be highly biased since inability to perform one's major activity, such as work, is a significant life event and its timing is probably more easily recalled than the onset of the condition that causes it. In a small number of cases, however, the duration of time disabled was inconsistent with the age of the respondent and was treated as missing. The percentage of the sample with missing information on duration and age at onset was 4.6 percent in 1969-81 and 2.0 percent in 1979-81.

Table 2 shows trends in rates of incidence and prevalence of persons unable to perform their major activity by age for persons 17 and over. Ages 17-64 show increases in both incidence and prevalence, consistent with rising rates of work disability in that age group. In the elderly, incidence declined at all ages. Prevalence increased at ages 65-74, but declined among those 75 and over.

Figure 2 shows the percent distribution of the age of onset of inability to perform major activity. There is a clear shift in the age of onset to earlier ages. Two prominent peaks are observed at ages 62 and 65, with a clear shift in the latter period away from age 65 to age 62. This trend is consistent with increasing earlier retirement and rising work disability prevalence.

At the same time, the duration of disability has increased, as Figure 3 shows. There is a decline in the percentage of persons unable to perform their major activity under two years and an increase in those so disabled for 5 or more years.

Table 3 shows trends in the median and mean duration of inability to perform major activity controlling for the age of onset. For ages 45 and over, there has been a significant increase in the duration of time persons report being unable to perform their major activity - about a half of a year over this approximately 10-year period.

These data convey two points: (1) there has been an apparent shift in severe disability, primarily inability to work, to earlier ages; and (2) that persons are reporting being severely disabled for longer amounts of time. There are also at least two problems with the data: (1) there has been a decline in the number of persons who fail to answer the duration question; and (2) persons who died, recovered, or went into institutions, are not included in the data, so incidence rates and duration may be biased.

If persons with long durations failed to answer the question in the earlier period, but answered more frequently in the latter period, this could explain at least part of the increase in duration. Unfortunately, this cannot be examined any further here. Declining mortality might complicate the picture if, for example, persons with short durations may be more likely to recover now than in the past, leaving a greater proportion of persons disabled for long durations, even though their survival may remain unchanged.

It is impossible to disentangle these complicating factors with the data at hand. We can, however, obtain some additional insight by examining changes in other indicators of disability. Figure 4 shows changes in the mean number of restricted activity days by degree and duration of limitation. Restricted activity days are days on which persons cut down on their usual activities. The highest number of restricted activity days are reported by persons unable to perform their major activity. Figure 4 shows that restricted activity days increased significantly among persons unable to perform their major activity. This suggests that severely disabled persons have experienced more difficulty in performing their activities rather than less under conditions of declining mortality.

Figure 4 also demonstrates that there is a significant elevation of activity restriction in the first year of disability, but after the first year, the level is fairly constant. The same pattern is seen for bed disability days (Figure 5) and for hospital episodes (Figure 6). It appears that persons are reporting greater disability and are more likely to be hospitalized in the first year.

To summarize, there does not seem to any evidence that the mortality experience of the more severely disabled persons in the working age population is different from the rest of the population. Household interview data, however, shows a definite shift in severe disability to earlier ages, and there is some evidence to suggest that persons may be surviving longer with serious disabilities. It is difficult to conclude this in the absence of supporting data on changes in disability incidence and duration for deceased or institutionalized persons who are not included in the sample. However, persons reporting severe disability also report consistently more difficulty in performing their usual activities over this time period. At the very least, this suggests that persons who are unable to work or perform housework are not more casually adopting the disability role.

The fact that disability and medical care use is significantly elevated in the first year underscores a major problem in disability policy. Under SSDI, due to eligibility provisions, beneficiaries become entitled to Medicare too long after the initial precipitating event that causes disability has taken place. Restricted activity days, bed disability days, and hospital episodes are all significantly elevated in the first year. Others have also noted that mortality is highest in the first year under SSDI (Kelley, 1984). It is probable that the survival and quality of life of SSDI beneficiaries would be significantly improved if their health problems were covered more adequately in the first year when such assistance is so apparently needed.

In order to definitely address the question of whether the age at onset of disability is occurring earlier or later in life as people survive longer requires longitudinal data on functional ability and other measures of activity restriction that incorporate changes in survival and institutionalization, and are collected over an extended period of time. It is promising that a number of longitudinal data collection efforts are now underway that will help to answer this question.

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TABLE 1: TRENDS IN MORTALITY RATES PER 1,000 PERSONS OF SSDI BENEFICIARIES COMPARED TO THE TOTAL POPULATION, BY AGE AND SEX, 1970 TO 1985

	Males, Age Group:					Females, Age Group:				
	15-24	25-34	35-44	45-54	55-64	15-24	25-34	35-44	45-54	55-64
SSDI Population										
1970[1]	26.2	32.3	42.8	63.0	80.3	33.1	33.3	37.8	49.4	51.9
1985[2]	25.4	24.6	32.9	52.3	64.6	25.3	22.6	32.8	44.5	45.2
Percent Change	-3.1	-23.8	-23.1	-16.9	-19.6	-23.6	-32.1	-13.2	-9.9	-12.9
Total Population										
1970[3]	1.9	2.2	4.0	9.6	22.8	1.7	1.0	2.3	5.2	11.0
1985[4]	1.4	1.8	2.9	6.7	16.9	0.5	0.7	1.4	3.7	9.3
Percent Change	-26.3	-18.2	-27.5	-30.2	-25.9	-28.6	-30.0	-39.1	-28.8	-15.5
Ratios of SSDI Mortality to Total Population Mortality										
1970	13.8	14.7	10.7	6.6	3.5	47.3	33.3	16.4	9.5	4.7
1985	18.1	13.7	11.3	7.8	3.8	50.6	32.3	23.4	12.0	4.9

Sources:

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TABLE 2: ONE YEAR AVERAGE INCIDENCE AND PREVALENCE RATES PER 1,000 TOTAL POPULATION FOR PERSONS LIMITED IN ACTIVITY, BY DEGREE OF LIMITATION AND AGE, 1969-71 AND 1979-81 AND PERCENT CHANGE

	1969-71:				1979-81:				Percent Change in:	
Age	Incidence Number	Population (1,000s)	Incidence Rate	Prevalence Rate	Incidence Number	Population (1,000s)	Incidence Rate	Prevalence Rate	Incidence Rate	Prevalence Rate
17-44	202606	72897	2.78	9.08	302882	93511	3.24	11.52	16.54	26.87
45-64	466689	41269	11.31	44.39	522659	43724	11.95	65.54	5.70	47.65
65-74	252243	11858	21.27	126.86	282029	15251	18.49	143.4	-13.07	13.04
75-84	176726	5982	29.54	206.37	186066	7157	26.00	198.34	-12.00	-3.89
85+	50381	1161	43.39	345.41	59913	1620	36.98	327.46	-14.77	-5.20

Source: National Health Interview Surveys, 1969-71 and 1979-81: original tabulations from public use tapes

TABLE 3: MEDIAN AND MEAN DURATIONS OF INABILITY TO PERFORM MAJOR ACTIVITY, BY AGE OF ONSET, 1969-71 AND 1979-81 AND DIFFERENCE BETWEEN PERIODS

	1969-71			1979-81			Difference in
Age of onset	Median	Mean	SE	Median	Mean	SE	Mean
Under 45	6	10.6	0.26	6	10.8	0.23	0.2
45-54	5	7.7	0.22	6	8.4	0.18	0.7*
55-64	4	6.2	0.12	5	6.9	0.11	0.7*
65-74	4	5.7	0.12	5	6.2	0.14	0.5*
75+	3	3.8	0.10	3	4.3	0.14	0.5*

*Significant difference at p<=.05

Note: Standard errors reflect simple random sampling assumptions and do not correct for complex survey design

Source: National Health Interview Surveys, 1969-71 and 1979-81: original tabulations from public use tapes

FIGURE 1: TRENDS IN MORTALITY OF SSDI BENEFICIARIES COMPARED TO TOTAL POPULATION AGES 15-64, 1970-1985

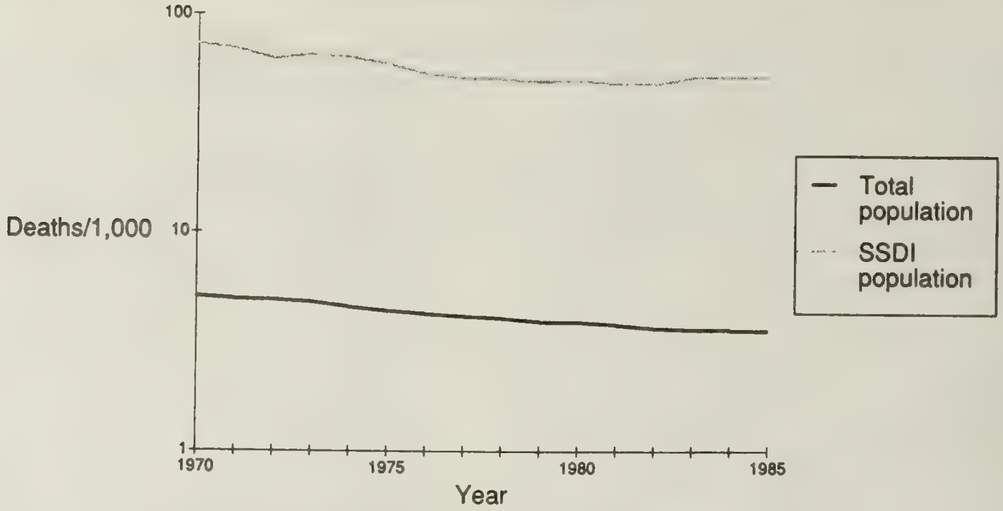


FIGURE 2: DISTRIBUTION OF THE AGE AT ONSET OF INABILITY TO PERFORM MAJOR ACTIVITY, 1969-71 AND 1979-81

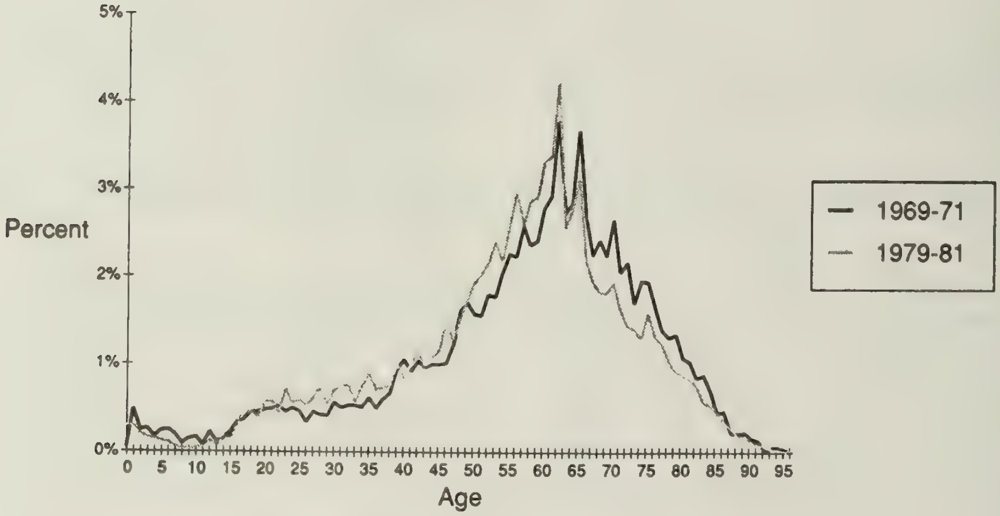


FIGURE 3: DISTRIBUTION OF THE DURATION OF INABILITY TO PERFORM MAJOR ACTIVITY, 1969-71 AND 1979-81

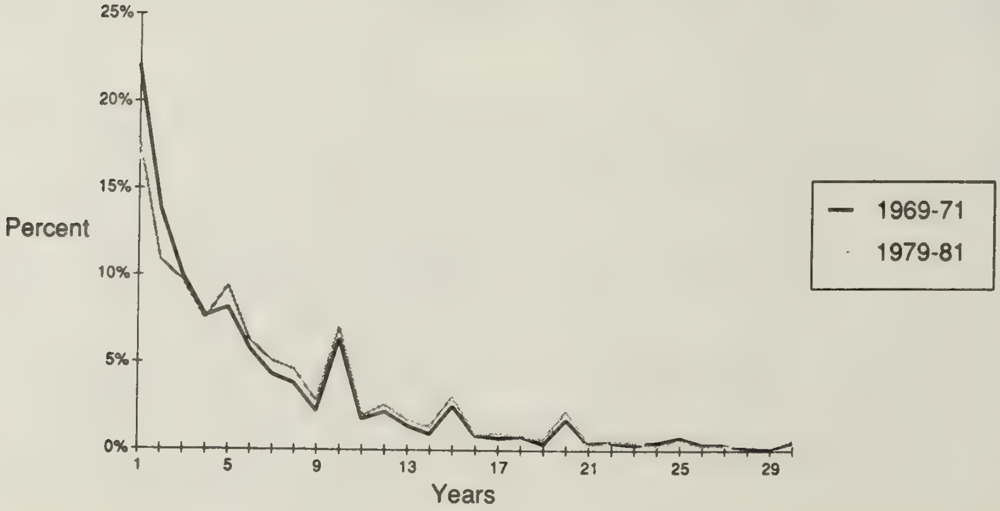


FIGURE 4: MEAN NUMBER OF RESTRICTED ACTIVITY DAYS, BY DEGREE AND DURATION OF LIMITATION, 1969-71 AND 1979-81

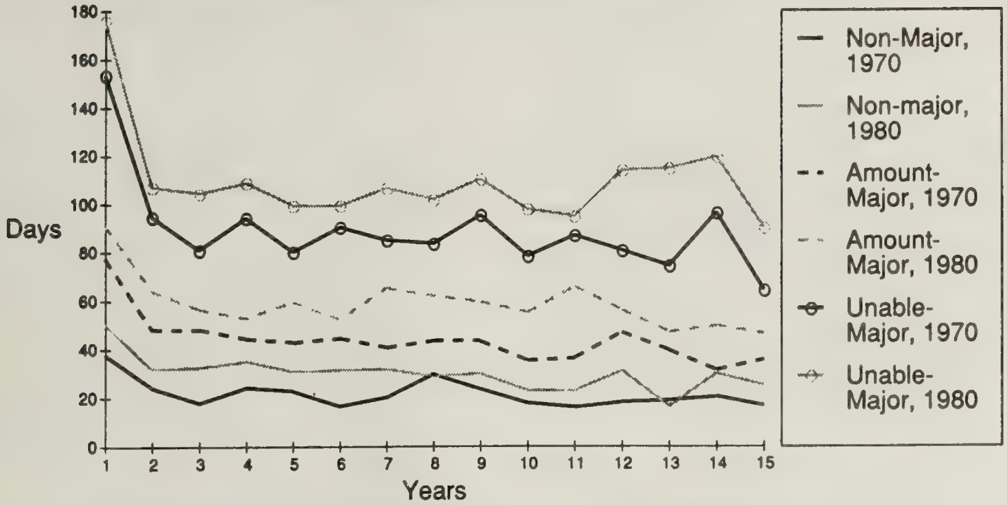


FIGURE 5: MEAN NUMBER OF BED DISABILITY DAYS, BY DEGREE AND DURATION OF LIMITATION, 1969-71 AND 1979-81

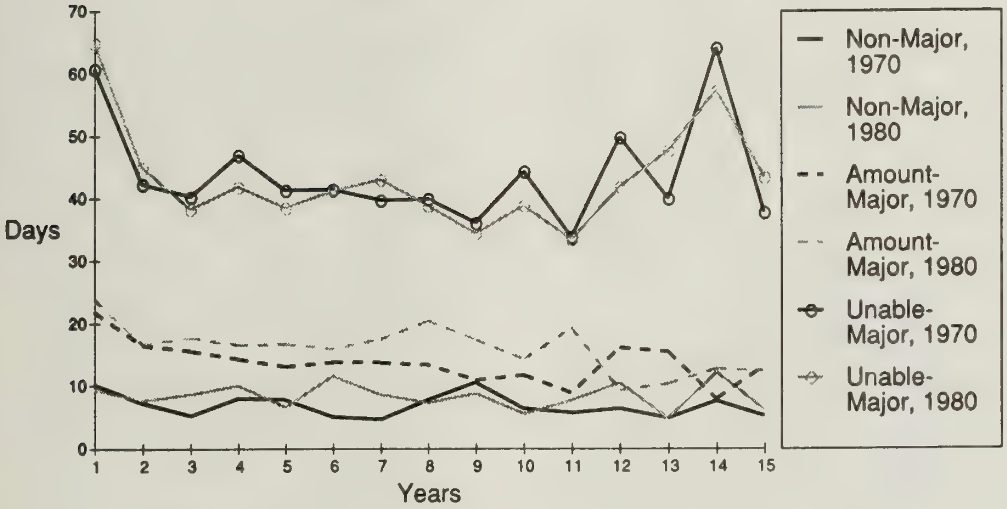
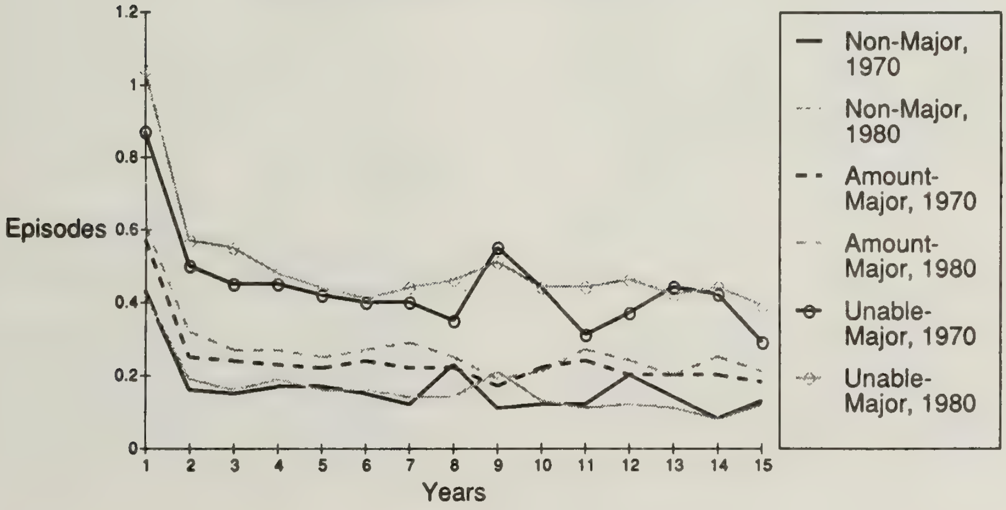


FIGURE 6: MEAN NUMBER OF ANNUAL HOSPITAL EPISODES, BY DEGREE AND DURATION OF LIMITATION, 1969-71 AND 1979-81



The Relationship between Selected Major and Minor Health Conditions and Work-Retirement Status among the Elderly

Patricia L. Colsher, Lorraine T. Dorfman, and Robert B. Wallace
The University of Iowa, Iowa City, IA 52242

Although it is known that global ill health is related to work-retirement status among the elderly, relatively less is known about the impact of specific health problems on the decision to continue working or to retire. We explored the relationship betwen specific major and minor health problems and work-retirement status among the elderly (aged 65 and older), and examined the role of self-perceived health, functional status, and global mood in mediating the relationship between specific illnesses and work-retirement status.

Previous research has shown that ill health can be used as a predictor of the decision to retire as well as of various outcomes of retirement, such as subsequent health status and psychosocial status. Although this knowledge is useful, it does not provide a complete description of the relationship between health and work-retirement status. Specifically, the experience of health problems is a multidimensional phenomenon. Health problems themselves differ with regard to such factors as how life-threatening they are, the nature of their symptoms, the types of treatments which are required, and the extent to which they force life-style changes. Illness-specific factors, in conjunction with the individual's global and specific preconceptions about illness and other situational factors, then determine the individual's response to illness. Thus a thorough understanding of the relationship between ill-health and work-retirement status would be aided by the investigation of specific illnesses as opposed to global health. Recently, for example, Cartwright and Cornoni-Huntley (1986) demonstrated that work-retirement status varied across large categories of diseases (heart and respiratory diseases, arthritis, and cancer) among men.

The present study examined the relationship between six specific major health problems, all of which present significant risks to the elderly and work-retirement status, as well as potential mediators of that relationship. Additionally, we examined the relationship between number of major and minor health impairments and work-retirement status.

METHOD

Respondents.

Respondents were participants in the Iowa 65+ Rural Health Study, a population-based survey of persons aged 65 and older in two rural Iowa counties. Of the total sample of 3673, 3097 respondents were given a lengthy in-person survey which consisted of demographic information, employment history, functional status, self-perceived health, mood, and a wide range of information about past and present health problems. In order to be included in the present analysis, respondents had to be either employed or retired from employment at the time of interview. Other persons, such as full-time housewives and persons who were on strike or laid off from but looking for employment, were excluded. All respondents were therefore classifiable as employed, retired for health reasons, or retired for reasons other than health. A total of 2123 respondents, 1149 men and 974 women, were included in the present study. The mean age for men was 73.7 years, and that for women was 73.6 years.

Items included and statistical analyses.

Three general sets of analyses were performed. The first set of analyses was intended to clarify the relationship between specific major health problems and work status. Respondents were asked whether they had ever been told by a doctor that they had a myocardial infarction, stroke, hypertension, cancer, diabetes, or hip fracture. Lifetime history rates for each of the health problems were computed without regard to the presence or absence of other illnesses. Risk of health-related retirement was also computed for each of the illnesses. In order to be included in this portion of the analysis, the respondent could have only one of the conditions of interest. Certain illnesses (e.g., stroke and hypertension) tend to cluster, and the restriction of these analyses was intended to increase analytic and conceptual clarity. A nominally-healthy control group, which reported none of the listed health conditions, was included.

The second set of analyses was intended to clarify the relationship between work-retirement status and self-perceived health (U.S. Bureau of the Census, Health Interview Survey, 1979), the Rosow scale of functional status (Rosow & Breslow, 1966), cognitive functioning, as measured by a 20-item recall task, and global mood. Work-retirement status and sex-specific analyses of covariance (with respondent age as covariate) were performed on the measures of self-perceived health, physical functional status, recall, and mood. Additionally, multiple regression analyses for work-retirement status were performed separately for each of the specific illnesses. These analyses were limited to those persons who had only one of the illnesses of interest. Age and sex were entered into the model first, and self-perceived health, functional status, and global mood were entered in the manner which both maximized their contribution to the model and ensured the inclusion of all three measures.

The final analyses were aimed at determining the relationship between number of major and minor health problems and work-retirement status. Two groups of major health problems, and one group of minor health problems of health complaints, as shown in Table 1, were examined. All of the analyses of the health conditions followed a similar pattern: work status (Retired-health: RH, Retired-other: RO, Working: W) by sex analyses of covariance with age as the covariate were performed.

Table 1
Enumerations of Health Problems

Major illness I: myocardial infarction, stroke, hypertension, cancer, diabetes, hip fracture

Major illness II: cataracts, glaucoma, Parkinson's disease, anemia, phlebitis, asthma, emphysema, chronic bronchitis, or other lung disease, stomach or intestinal ulcers, cirrhosis or other liver disease

Health complaints: pain or cramps in legs at night, indigestion or upset stomach, dry or itching skin, fallen arches or flat feet, bunions, corns, or callouses on feet, other foot problems, trouble with fingernails or toenails, pain in any joints, joint stiffness upon awakening, arthritis or rheumatism, kidney or bladder trouble

Table 2
Lifetime History Rates of Illnesses

	RH	RO	W
Men			
MI	36.2	15.9	16.2
Stroke	12.8	5.8	3.9
HT	37.0	30.9	32.8
Cancer	19.3	12.0	11.1
Diabetes	17.3	7.7	10.3
Hip Frac.	4.5	2.0	1.2
Women			
MI	16.3	6.1	5.6
Stroke	11.1	4.2	1.6
HT	55.6	46.1	45.8
Cancer	16.3	14.1	14.7
Diabetes	16.3	7.7	8.0
Hip Frac.	7.2	5.3	2.8

RESULTS

Characterization of the work-retirement groups and lifetime history rates for specific major illnesses

Age-adjusted sex and work-retirement status specific lifetime history rates per 100 for myocardial infarction (MI), stroke, hypertension (HT), cancer diabetes, and hip fracture (Hip Frac.) are shown in Table 2. As may be seen, rates are highest among those men and women who retired for health reasons, and differ little between those who retired for reasons other than health and who were still working.

Turning briefly to the measures of self-perceived health status (SPHS), physical functional status (FS), recall, and mood in Table 3, it can be seen that those men who retired for health reasons rated their own health as poorer, reported poorer physical functioning, were in poorer moods, and performed worse on the recall task than the other groups of men. The same pattern of differences was found among women. The differences between the RH respondents and the RO and W respondents were consistently statistically significant.

Table 3
Sex and Work-Retirement Status Specific,
Age-Adjusted Psychobehavioral Status

	RH	RO	W
Men			
SPHS	2.7	2.0	1.9
FS	3.9	3.3	3.3
Mood	1.5	1.4	1.3
Recall	4.3	4.6	5.0
Women			
SPHS	2.5	2.0	1.9
FS	4.0	3.5	3.3
Mood	1.6	1.5	1.5
Recall	5.2	5.8	5.7

Major health problems and work-retirement status.

The majority of men and women, whther suffering from one of the specific health impairments or nominally healthy, were retired. The pattern of work-retirement behavior, however, varied across illnesses and between men and women. The odds of health-related retirement for men and women as a function of each specific illness are summarized in Table 4. Recall that the persons included in these analyses had only one or none of the conditions. The 95% confidence intervals indicate significantly increased probabilities of health-related retirement among men for myocardial infarction, stroke, and diabetes. Among women, significantly increased probability of health-related retirement was associated with cancer, diabetes, and hip fracture. Cancer was associated with a non-significant increase in health-related retirement among men, and hypertension and stroke were associated with non-significant increases in health-related retirement among women. Retirement for reasons other than health was not associated with any of the specific conditions.

Table 4
Illness Specific Odds Ratios of Health-Related Retirement for Men and Women

	N	OR	CI
Men			
MI	91	2.49	1.76-3.22
Stroke	14	2.79	2.11-3.47
HT	190	1.07	0.70-2.04
Cancer	61	1.54	0.86-2.22
Diabetes	43	2.00	1.31-2.69
Hip Fracture	8	0.98	0.32-1.64
Women			
MI	15	0.67	0.08-1.26
Stroke	8	1.25	0.65-1.85
HT	258	1.39	0.75-2.03
Cancer	54	1.66	1.04-2.28
Diabetes	17	1.76	1.16-2.36
Hip Fracture	21	3.80	3.16-4.44

Multiple regressions

The multiple regression analyses relating work-retirement status to age, sex, self-perceived health, the Rosow scale of functional status, and a global mood rating indicated differences among the illnesses. Age and sex together were typically not especially potent predictors, accounting for 1.4, 3.8, 4.2, 3.8, 4.1, and 9.9 percent of the work-retirement status variance for MI, stroke, hypertension, cancer, diabetes, and hip fracture, respectively. For the cardiovascular illnesses, SPHS was a superior to FS as a predictor, accounting for 12.9, 15.0, and 4.1% of the variance for MI, stroke, and hypertension. On the other hand, for noncardiovascular illnesses, FS was superior to SPHS, accounting for 12.3, 23.4, and 18.8% of the variance for cancer, diabetes, and hip fracture, respectively. Mood was not typically a potent predictor, accounting for only 3.8% of the variance among the stroke patients, but less than 1% among the other groups.

Multiple health problems and work-retirement status.

Also of interest are the relationships between number of major and minor health problems and work-retirement status. As may be seen in Table 5, the number of major illnesses was highest among RH person, regardless of sex, and the number of minor complaints was highest among RH women, but differed little among the work-retirement groups for men. The work status x sex analysis of covariance (with age as covariate) performed separately on the number group I and group II major illnesses obtained significant effects of work status, resulting from the large number of illnesses reported by those individuals who retired for health reasons as compared to either those who retired for other reasons or those who were still working. The work status by sex ANCOVA performed on the number of minor health complaints obtained a significant effect of sex as well as a work status by sex interaction. The interaction resulted from the high level of complaints reported by women who retired for health reasons compared to the women who retired for other reasons, but the absence of an effect of work status for men.

Table 5
Sex and Work-Retirement Status Specific, Age Adjusted Mean Number of Illnesses

	RH	RO	W
Men			
Group I	1.3	0.7	0.8
Group II	1.1	0.7	0.7
Complaints	4.2	4.3	4.0
Women			
Group I	1.2	0.8	0.6
Group II	1.3	0.9	0.6
Complaints	5.3	4.6	4.9

DISCUSSION

The intent of this paper was to characterize the relationship between specific health problems and work-retirement status among elderly persons. By investigating specific health problems, as opposed to the more typical approach of global ratings of health, it is possible both to obtain a more detailed understanding of the relationship between health and retirement, as well as to determine those aspects of disease which are associated with retirement. In general, we found that myocardial infarction, stroke, cancer, and hip fracture were associated with higher rates of retirement among men, and myocardial infarction, stroke, hypertension, cancer, and hip fracture were associated with higher rates of retirement among women. Men with reported histories of myocardial infarction, stroke, or diabetes had a significantly greater probability of health-related retirement than did the nominally-healthy controls, as did women with histories of diabetes, cancer, or hip fracture. Our findings with regard to cardiovascular disease among men are congruent with those of Cartwright and Cornoni-Huntley (1986), who demonstrated increased retirement among men with heart disease. In addition, we were able to expand upon their findings by including women as well as men in our study, and by including additional health problems.

Both self-perceived health and functional status were important predictors of the relationship between specific diseases and work-retirement status, although their roles differed with different illnesses. That is, functional status was relatively more important for cancer, diabetes, and hip fracture, whereas self-perceived health was relatively more important for myocardial infarction and stroke. This indicates that, as might be expected, functional limitations can force retirement. Self-perceived health, on the other hand, is a somewhat more complex and subtle measure. That is, functional status was measured in the present study as the simple ability or inability to walk up and down a flight of stairs, walk a half mile, and do heavy work around the house. Self-perceived health, however, is a function of both the individual's objective physical status and their subjective evaluation of their physical status. Our findings suggest the importance of including both objective and subjective measures of health in studies of health related retirement.

Persons who had retired for health reasons reported greater numbers of serious illnesses than did the other work status groups, which differed little, and the lifetime history rates of major illnesses were highest among persons who had retired for health reasons but differed little between those who had retired for reasons other than health and those who were working. Similarly, the psychobehavioral status of persons who retired for their health was impaired compared to the other groups, but that of persons who retired for other reasons and those who were still working was similar. Investigation of additional factors, such as financial incentives and the psychological meaning of work to the individual may clarify why persons with similar physical and psychological characteristics choose either work or retirement.

Like other investigators, we are troubled by the difficulty in determining whether illness, even when its onset precedes retirement, is actually causally related to retirement or is used as a convenient excuse for retirement. The consistency of our findings with regard to the rates of specific illnesses and the physical functional, affective, and cognitive impairments among persons who retire for their health suggests that this latter interpretation, which characterizes at least some of the persons who retire for their health as malingerers, must take a strong stand with regard to the malingering. That is, persons who retired for their health were impaired over a wide range of behaviors. The "malingering" interpretation would therefore have to encompass all of these behaviors. On the other hand, it is possible that persons who retire for their health are impaired over such a wide range of function that working genuinely constitutes an excessive burden for them.

It is important to note some potential limitations in the present study. Although we have demonstrated that certain major illnesses are differentially associated with health-related retirement, we have done so in a cross-sectional design, and are thus unable to make causal inferences. Obviously longitudinal investigations of the obtained relationships is in order. Additionally, in the analyses limited to persons with only one of the conditions, we had small samples (e.g., hip fracture among men). The use of larger samples might indicate the presence of additional differences among specific illnesses and mediators. Our use of self-reports of illness may have introduced some inaccuracy.

To summarize, it is clear that different illnesses are differentially associated with work status even when the illnesses are all potentially life-threatening, and that different mediators are involved with different diseases. Our findings on the relationship between specific health conditions and work-retirement status suggest that both health-care professionals and retirement counselors have important educational responsibilities in dealing with health-impaired elderly. Health-care professionals may be able to target some individuals (e.g., men with myocardial infarctions or strokes, women with cancer) as being more likely to retire, and thus may provide such persons with the opportunity for health-specific pre-retirement education. The potential long-term impact of illnesses on employability needs to be discussed with individuals who are not yet of retirement age but who are at risk for health-related retirement. Retirement counselors, on the other hand, ought to be aware that certain retirement groups (i.e., those who retire for their health) may need more information about health care (e.g., specific programs available for the elderly, financial aspects, information about specific health problems) than do other groups. Awareness of these factors may both improve the quality of life of the elderly and allow more effective allocation of public and private health care and pension resources.

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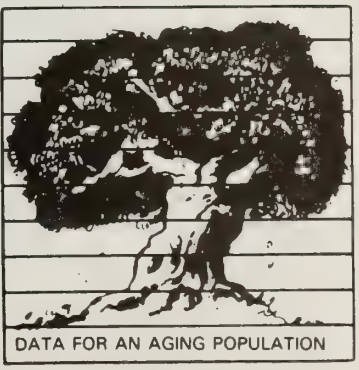
Session E

Techniques for Analyzing Longitudinal Data


DATA FOR AN AGING POPULATION

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A GRADE OF MEMBERSHIP APPROACH TO EVENT HISTORY DATA

H. Dennis Tolley, Brigham Young University and Kenneth G. Manton, Duke University

I. INTRODUCTION

This paper discusses the use of grade of membership methods to analyze event history data. By 'event history data' we mean data collected on individuals over time such that the data has the following characteristics:

1. The response of each individual is independent of each other individual.
2. A response consists of a pair; a time the event occurs and the type of event that occurs.
3. Each individual may experience several events over time.
4. The probability of any type of event in a short period of time depends only on the following:
    a. The time since last event.
    b. The type of event the last event was.
    c. A set of concomitant variables peculiar to each individual.
5. There are only a finite number of possible event types.

In addition to the above specifications, we will consider data that satisfies the following constraints:

1. The events can be assumed to occur only at discrete points in time.
2. Individual concomitant information can change over time and hence such information is updated on each individual at discrete points in time.
3. The probability distribution for the next event, both time and type, depends only on the concomitant variables and the type and time of the last event.

With these assumptions and constraints, the probabiiities of the various types of events can be represented using an 'event table.' Such a table is like a series of multiple decrement life tables giving probability of decrement (occurrence of an event of some type) as a function of time. The analysis of event history data has recently developed as a methodology with a literature. References to those papers relevant to this paper have been reviewed by Manton et al. in Sociological Methodology, 1987.

The grade of membership (GOM) methods addressed in this paper follow the methodology developed by Woodbury and coworkers (see Woodbury et al., 1978). In this development, each individual's response is assumed to be a stochastic outcome based upon the individual's (unique) grade of membership scores. These grade of membership scores measure how much the individual resembles various 'pure type' classifications. By constraint 3, above, given these scores, the probability of an event (both time and type) does not depend on any other characteristic of the individual except time of last event and type of last event. As a consequence, grade of membership methods can be used whenever underlying pure type classifications are assumed to exist and where the natural heterogeneity of the individuals in the sample (and population) can be viewed as arising from deviations from these pure types.

Based upon the constraints considered above, the analysis of event history data can be viewed consists of the following components:

1. A set of pure types for the population. This represents the basis for grade of membership scores.
2. The set of event tables for each individual pure type. This gives the probabilities of each type of event as a function of the time since the last event and the type of the last event.
3. An algorithm for blending pure type event tables to construct an event table for each particular set of grade of membership scores. Thus, given the grade of membership scores of any individual, the event tables for this individual can be generated.
4. A method of determining the grade of membership scores for each individual given the concomitant variables.

This paper presents a method of obtaining each of these components as follows. First, given a fuzzy partition of the sample (i.e. the grade of membership scores), a method of estimating event tables using maximum likelihood methods is presented. This method naturally includes the dynamic changes in the concomitant variables by viewing the gathering of information at discrete points in time as one of the decrements. Second, methods of controlling for different forces of decrement are used to generate specific, pure type decrement tables. The methods of creating a fuzzy partition are then briefly reviewed. The paper concludes with an example.

II. PURE TYPE EVENT TABLE ESTIMATION

In this section, we present the method of estimating event tables for each individual. We assume that there exists a set of K pure type characteristics and each individual has some level of similarity or grade of membership to the groups defined by these pure types. For example, one pure type may be elderly (85 plus) females with severe disability but mentally active. Similarly, a second pure type may be young (65-70) physically strong, but senile males. Although no individual in the population of interest may be exactly like either pure type, each individual may have more or less of the characteristics of both pure types. The grade of membership scores, g_{ik} for individual i and pure type k, represent the degree to which the individual represents the kth pure type. If $g_{ik} = 1$, then the ith individual is completely like an individual of pure type k. Similarly $g_{ik} = 0$ means an individual does not resemble individuals of pure type k at all. Thus $g_{ik} \geq 0$ for k and for every individual i. Also $\sum_k g_{ik} = 1$.

In this section, we assume that g_{ik} values for $k = 1, \ldots, K$ are known for every individual i. These g_{ik} values may be based on exogenous data and estimated by some predetermined algorithm. One method of estimating g_{ik} using maximum likelihood techniques is given in the next section. Alternatively, the g_{ik} may be the result of expert clinical opinion which is justified only by the reasonableness of the classification scheme it produces. The reason for separating this section from the next is to keep clear the fact that the pure type event table estimation methodology does not require a GOM model estimation of the g_{ik} values. Thus, any set of 'reasonable' g_{ik} values can be used. The more 'reasonable' the better the modeling scheme.

We define the following:

j indexes the last event an individual has experienced, $j = 1, ..., J$. For example, $j = 1$ may represent well (no event), $j = 2$ represents entrance into a hospital, $j = 3$ represents entrance into a nursing home and so forth.

l indexes both the discrete time periods between events and the type of event, i.e., number of months after event j before the individual experiences another event, and the type of event the individual next experiences, $l = 1, ..., L_j$.

X_{ijl} = 1 if individual i last experienced event j and experiences event in a month, the pair indexed by l.

= 0 otherwise

λ_{kjl} = probability that an individual of pure type k with latest event j will experience l. The λ_{kjl} represents the event table parameters for state j for individual of pure type k. The l represents both time of the event and type of event. Thus, l can beconsidered as a double subscript. The λ_{kjl} parameters are what we wish to estimate.

p_{ijl} = Prob $\{X_{ijl} = 1\}$

Assumption 1 Given the g_{ik} values for individual i and the last event j, the next event is independent of any events in the past or future for individual i.

Assumption 2 The grade of membership scores, g_{ik} enter into the probability p_{ijl}through a linear blending of the λ_{kjl}, i.e.,

$$p_{ikl} = \sum_{k=1}^{K} g_{ik}\lambda_{kjl}. \qquad (1)$$

From the previous definitions, we note the following:

1. X_{ijl} has only one value of X_{ijl} which is nonzero for each values of j, overall values $l = 1, ..., L_j$.
2. For fixed j, the X_{ijl} are multinomial random variables; the cell probabilities given as p_{ijl}.
3. The likelihood function for all individuals is given by

$$L(x) = \prod_{i=1}^{I}\prod_{j=1}^{J}\prod_{l=1}^{L_j}\left\{\sum_{k=1}^{K} g_{ik}\lambda_{kjl}\right\}^{X_{ijl}}, \qquad (2)$$

where $\sum_{l} \lambda_{kjl} = 1$.

Equation (2) can be maximized, subject to the constraints using standard methods. Note that since we are here asuming that the g_{ik} are known, the likelihood is maximized only with respect to the λ_{kjl}.

Note that by constraint 2 in the introduction, we assume that concomitant information on each individual is changing over time and that these changes are updated at discrete time points. In practice, this updating step may or may not be done at regular intervals of time. In either case, given the updated data, the individual is assumed to behave as an independent individual. Therefore, the points in time where the concomitant data is updated is considered a decrement. In constructing pure type event tables this decrement is eliminated using the method of Chiang (1968).

III. ESTIMATING g_{ik} COEFFICIENTS

In the previous section, we illustrated how the likelihood equations could be set up for estimating the event table (the λ_{kjl})given the GOM scores g_{ik}. In this section, we briefly review how the g_{ik} scores can be estimated from exogenous categorical data. The methodology for this step is given in Clive and Woodbury (1978) and illustrated in several examples (see e.g., Woodbury and Manton, 1982). Therefore, this section only briefly highlights the steps involved.

The pure types are empirically defined from data observed on each individual. Thus, if the data is not relevant to the fuzzy partition which relates to the life table decrement, the pure type life tables will be about the same for each pure type. Therefore, the variability in decrement patterns observed in the various individuals will not be explained by differences in g_{ik} scores. This corresponds to non-significant regressor variables in the standard life table methods.

Suppose that on each individual J categorical variables are measured. Assume that the j^{th} categorical variable has L_j mutually exclusive and jointly exhaustive cells or outcome levels. For example, a variable $j = 1$ might correspond to sex of the individual, in which case $L_1 = 2$. Similarly, $j = 2$ may correspond to the level of disability observed as measured by the activities for daily living index (ADL). In this case, "1" may correspond to no ADL present, with "2" corresponding to one ADL and "3" corresponding to 2 or more ADL's present. Thus, $L_2 = 3$ in this case.

Similar to section II, we define the following:

X_{ijl} = 1 if the i^{th} individual has l^{th} level of categorical variable j.

= 0 otherwise

λ_{kjl} = probability that X_{ijl} is 1 if the i^{th} individual is of pure type k.

Then, with K and g_{ik} as defined before, we have the likelihood for the data observed on I 'individuals' as given by equation (2), with X_{ikl} and λ_{kjl} as defined here. Note that an individual person may be several 'individuals' in the data file since on each reassessment (conditional on the g_{ik}'s) he may be considered as another, independent data point on which event information is gathered.

Equation (2) is now maximized with respect to both the g_{ik} and the λ_{kjl} parameters. Also, in this case, equation (2) must be maximized subject to two sets of constraints,

$$\sum_{k} g_{ik} = 1, \text{ where } g_{ik} \geq 0,$$

and

$$\sum_{1} \lambda_{kjl} = 1, \text{ where } \lambda_{kjl} \geq 0.$$

The resulting estimates of g_{ik} are the GOM scores used in section II. Once the λ_{kjl} values for the life tables are estimated, the g_{ik}'s can be used to blend these life table parameters to create a life table for the specific individual.

IV. EXAMPLE: MEDICAID WAIVERED LTC SERVICES

As an example of the methodology described above, consider the Multipurpose Senior Services Program (MSSP). This project was designed for certain Medicaid recipients in California, and is intended to be the model for the reform of long term care service delivery in California.[1] Its purpose is to provide case management and other home and community-based services to an impaired elderly population. These services are intended to be substitutes for nursing home care. The program is a service delivery and financing mechanism. It consists of case management and purchased waivered services (services not normally paid for by MediCal such as home delivered care, security devices, respite care, etc., as required by the client's condition). Case management involves the coordination and supervision of the services (medical and non-medical) provided to a client. A case manager should be aware of the services available in a particular community and know how to gain access to these services.

Each individual in the study was assessed by an instrument designed to measure functional and health status. In addition, each individual was followed over time as to changes in health status, as reassessed periodically, and events such as entering a hospital or nursing home or death (see e.g. Tolley, Vertrees, and Manton 1987). Each individual's experience was broken into episodes defined as the time between events, where reassessment was considered an event. A control group was also included in the followup. These individuals were neither a matched nor random sample, but represented a group of individuals where the same assessment instrument was used at approximately the same frequency as in the MSSP group.

Based on the assessment - data available for each episode, a grade of membership model was fit as described in section III. As a result of this fitting, 5 pure types were identified. Briefly these pure types are characterized as follows:

1. Very old, very impaired people.
2. Very old widows.
3. Younger males, often Hispanic.
4. Healthy females living alone.
5. Acutely ill individuals.

Naturally, there are more characteristics to each of these pure tyupes. However, these short word descriptions are adequate here (see Tolley, Vertrees, and Manton 1987). The g_{ik} values for each episode of individual in the sample estimated, we can now estimate the event table for each of these pure types.

Using the methods illustrated in section II, the event table parameters $\hat{\lambda}_{kjl}$ are estimates of the multinomial probability of the l^{th} cell of the j^{th} multinomial for an individual of the k^{th} pure type. Recall the l is really a double subscript giving both the month of event and type of event. In the present scenario, we divide l into two indexes, the first, say l_1, giving the month of decrement and the second, say l_2, giving the state, i.e., 'hospital,' 'nursing home,' and 'death,' while eliminating 'reassessment,' and 'end of study,' using the Chiang cause elimination technique.

To form the life table, let $q_{jk}(l_1, l_2)$ be the probability that an individual of pure type k will experience event l_2 during the next month given his last event was j experienced at the beginning of month l_1. These event tables can be constructed from the multinomial probability estimates by recalling that, in order for someone to decrement, say at the second month by going into the hospital, he must first fail to be decremented during the first month.

Thus, $q_{jk}(1, l_2) = \lambda_{kjl}$, where $l = (1, l_2)$, but

$$q_{kj}(2, l_2) = \frac{\lambda_{kjl}}{1 - \sum_{l^*} \lambda_{kjl^*}} ,$$

where $l = (2, l_2)$ and the sum is over all values of l^* such that $l^* = (1, l_2)$ for any l_2. Similarly, values of $q_{jk}(m, l_2)$ for $m \geq 2$ are formed by

$$q_{jk}(m, l_2) = \frac{\lambda_{kjl}}{1 - \sum_{l^*} \lambda_{kjl^*}} ,$$

where $l = (m, l_2)$ and where the sum is over all values l^* such that $l^* = (m', l_2)$ for any l_2 and for any integral m' such that $0 < m' < m$. The overall probability of decrement is

$$q_{jk}(m) = \sum_{l_2} q_{jk}(m, l_2),$$

where the sum is taken over all values of l_2. From the event table probabilities we can make adjustments for certain types of censoring events. In Table 1 we present event tables prior to controlling for censoring due to a) re-assessment, b) drop-out, and c) end of study.

This table includes all decrements from the community to the hospital, to nursing homes, and death as well as forms of censoring. Exits from nursing homes and hospitals to the community and elsewhere were also estimated, but since the purpose of this chapter is to illustrate the method, not to present an evaluation of the MSSP program, these runs are not included in Table 1. This table, then, presents a partial picture of the flow of services and people for both waiver clients and controls. Elimination of the events (decrements) due to reassessment and so forth can be accomplished using Chiang's method.

V. DISCUSSION

The above analysis showed how the experience of a LTC population regarding events associated with use of health provider services could be characterized by a set of event tables for multivariate defined case mix population groups. The essence of the procedure was to form case mix indices for individuals using a fuzzy partition procedure and calculate multiple decrement life tables conditional on those values. We showed the general statistical theory by which tests of life table parameters could be formed and which censoring events could be adjusted for using standard Chiang type cause elimination adjustments. The life table estimates can be used to model more general stochastic processes where the Markovian assumptions (i.e., that the g_{ik}'s fully describe the state of the individual) fail and more general types of duration dependence are manifest.

Utilizing the way in which the data were gathered and used in estimating the life tables, we have used both 'end-of-study' and 'reassessment' as decrements. To eliminate these sources of decrement in a life table we employed independent competing risk procedures. Thus we see that the proposed procedure is quite general in that it can represent both a very detailed and complex health state in the construction of the g_{ik}'s and it can represent a quite detailed service use transition history in life tables constructed from the external λ_{kjl}.

The fuzzy boundary approach for classifying persons in terms of their risk for various kinds of service need is potentially much more powerful than fixed boundary groups like Diagnosis Related Groups. The results reported above indicate that fuzzy boundary concept could be used with event tables as a case mix index for service use. The resultant groups are able to predict differential service use for the pure types. Thus, this strategy for assessing the case mix of an enrolled population has a great deal of potential utility, not only for insurers who wish to provide insurance for long term care but also for entities like retirement communities and Social Health Maintenance Organizations which combine the functions of long term care insurer and provider.

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TABLE 1

Month	Pure Type I l_x	Pure Type I d_x	Pure Type II l_x	Pure Type II d_x	Pure Type III l_x	Pure Type III d_x
0	100000.	35980.	100000.	13008.	100000.	39890
1	64020.	10397.	86992.	11113.	60110.	20734.
2	53623.	9306.	75879.	6733.	39377.	6095.
3	44317.	4178.	69147.	12330.	33282	7990.
4	40140.	6477.	56817.	8222.	25292.	97.
5	33663.	9348.	48595.	18324.	25195.	7280.
6	24315.	8060.	30270.	16445.	17915.	8407.
7	16255.	4985.	13826.	3749.	9509.	160.
8	11270.	2256.	10076.	2392.	9348.	896.
9	9014.	1256.	7685.	1799.	8452.	3936.
10	7758.	2290.	5886.	1231.	4516.	5.
11	5468.	2233.	4655.	68.	4511.	626.
12	3235.	1004.	4586.	1404.	3885.	3885.

Month	Pure Type IV l_x	Pure Type IV d_x	Pure Type V l_x	Pure Type V d_x
0	100000.	15786.	100000.	32625.
1	84214.	8991.	67376.	21966.
2	75222.	9440.	45410.	18772.
3	65782.	9130.	26638.	11696.
4	56652.	14046.	14942.	9457.
5	42606.	13918.	5485.	1202.
6	28688.	19219.	4284.	3364.
7	9469.	5609.	920.	0.
8	3860.	591.	920.	0.
9	3268.	0.	920.	0.
10	3268.	182.	920.	223.
11	3086.	1759.	697.	434.
12	1327.	300.	262.	0.

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[1] State of California Waiver Application, Health and Welfare Agency, Department of Health and Welfare Agency, Department of Health Services, March 3, 1983, p.4.

INVESTIGATING TEMPORAL ASYMMETRIES IN LONGITUDINAL STUDIES WITH DIFFERENTIAL EQUATION MODELS

James H. Dwyer and David P. MacKinnon
University of Southern California

Longitudinal data are collected to achieve one or more of several goals. One goal is to explore the temporal relation of changes in variables. Interest in these temporal patterns stems from the fundamental goal of science: to determine causal relations. The need to explore temporal patterns thus arises when an association between two variables is not explained by other observed variables, but the directionality of causal influence is in question. Longitudinal observation can be of assistance in this regard since it is generally assumed that change in the causal variable precedes change in the effected variable.

Suppose that Y is the risk of coronary heart disease (CHD) and X is systolic blood pressure (SBP). The finding that Y and X are positively correlated raises the prospect that elevated SBP increases the risk of CHD and/or that CHD elevates SBP. The most unambiguous way to resolve the directionality issue is to randomly manipulate each variable and observe the consequences. However, prior to such clinical studies, it would be useful to know if a rise in SBP precedes an elevation in the risk of CHD, or vice versa. Prospective studies such as Framingham (Castelli, et al) serve this goal. The finding that "disease-free" hypertensives are subsequently at higher risk for CHD than disease-free normotensives diminishes the plausibility of an explanation of the CHD-SBP association as due entirely to a causal process that leads from CHD to SBP.

The proportional hazards model (Cox, 1972) provides a statistical tool for summarizing relations among longitudinal observations of an absorbing category (e.g., specific cause mortality or morbidity) and baseline observations of a risk factor. Extensions of this model also allow incorporation of longitudinal observation of risk factors (cf Breslow, 1988). The form of the model is in terms of the hazard of failure at time t. The hazard is the first derivative of time path of survival with respect to time. Let P(t) be the number of persons in a cohort surviving to time t. Then, if P(t) is differentiable, $(-dP/dt)(1/P)$ defines the hazard rate at time t: the conditional probability of failure per unit time. The goal of statistical analysis is then to estimate relations between this continuous time derivative and suspected determinants of failure.

Now suppose that the variables of interest are two continuous variables such as SBP and relative weight (RW), where neither is an absorbing category. A cross-sectional association between the two raises the prospect of a causal relation between them, and the issue of causal directionality arises. A useful first step toward investigating this relationship would be to explore the temporal pattern of changes in the two variables: does a rise in RW the SBP/CHD question since it is not possible to begin observation at a point analogous to the disease-free status that characterizes prospective studies of chronic diseases such as CHD. Rather, observation of adolescents or adults implies a starting point that involves variability in both SBP and RW. This means that the directionality issue must be addressed by the data — rather than being determined by the design of the study.

2. A continuous time differential equation model

One model that may be used to investigate the temporal relation of changes in two continuous variables observed longitudinally is somewhat analogous to the hazard function, in that it involves continuous time derivatives (with respect to time) as the dependent variables. The simplest form of the model is

$$dY/dt = a_1 + \alpha X(t) \qquad (1.1)$$

$$dX/dt = b_1 + \beta Y(t) \qquad (1.2)$$

where dY/dt (or dX/dt) is the first derivative of the time path Y(t) (or X(t)). The time path of a variable is simply its level as a function of time. For example, SBP(t) would be the level of SBP at time t, where t may be defined as chronological age. Equations 1.1 and 1.2 imply that the level of X influences the rate of change in Y to the extent α, and the level of Y influences rate of change in X to the extent β. As a simple example, suppose that β=0 and X increases linearly with time

$$X(t) = b_0 + b_1 t \qquad (2.1)$$

Then

$$dY/dt = a_1 + \alpha(b_0+b_1 t)$$

and

$$Y(t) = a_0 + \alpha b_0 t + \alpha b_1 t^2/2 \qquad (2.2)$$

If X and Y are measured at t=0 and t=1, then

$$b_0 = X(0)$$

$$b_1 = X(1) - X(0)$$

$$a_0 = Y(0)$$

$$\alpha = [Y(1)-Y(0)]/[(X(0)+X(1))/2]$$

Thus, α could be estimated with observations at two points in time if β is presumed zero. Note that equations 2.1 and 2.2 imply growth of both X and Y without bound.

But now suppose that X and Y influence each other in a reciprocal manner such that α and β are both non-zero. Then, if a_0 and b_0 are zero,

$$\int dy = Y(t) = \int \alpha X(t)dt = \int \alpha \int \beta Y(t)dt \cdot dt = \cdots$$

$$\int dx = X(t) = \int \beta Y(t)dt = \cdots$$

which implies that $Y(t) = e^t$ and $X(t) = e^t$ when $\alpha = \beta = 1$. When $\alpha = -1$ and $\beta = 1$, the time paths are sine and cosine functions of t.

A major drawback of these equation systems for modelling biological systems can be seen in equation 2.1. Suppose that dX/dt is zero. This implies that b_1 is zero and that Y(t) increases linearly with time if b_0 is non-zero. However, in the case of a causal relation between RW and SBP, we would expect an elevated RW to produce a rise in SBP that reached a new equilibrium point after some period of time. This aspect of the system can be incorporated into the differential equation model by allowing the level of each variable to "feed back" to its own rate of change. Thus the model is in the form

$$dY/dt = a_1 + \alpha_1 X(t) + \alpha_2 Y(t) \qquad (3.1)$$

$$dX/dt = b_1 + \beta_1 Y(t) + \beta_2 X(t) \qquad (3.2)$$

where the parameters α_2 and β_2 reflect the negative feedback of the level of each variable upon its own rate of change. If Y and X are observed at t=0 and t=1, then it can be shown (cf Karlin & Taylor, 1981) that

$$Y(1) = a_1^* + \alpha_1^* X(0) + \alpha_2^* Y(0)$$

$$X(1) = b_1^* + \beta_1^* Y(0) + \beta_2^* X(0)$$

Now, when $\beta_1 = 0$ (the system is unidirectional),

$$a_1 = [e^{\alpha_2(t_1-t_0)}-1]a_1/\alpha_2$$

$$\alpha_1 = [e^{\alpha_2(t_1-t_0)}-1]\alpha_1/\alpha_2$$

$$\alpha_2^* = e^{\alpha_2(t_1-t_0)}$$

Thus, the parameters of equation model 3 can be estimated with observation of Y and X at two points in time. However, bias in these estimates can occur if the variables are measured with error, or if variables are left out of the model such that, for example, the extent of negative feedback is exaggerated. Thus, it is useful to have several measurement points when estimating equation model 3.

The differential equation models described thus far are unlikely to be realistic descriptions of many human biological processes since they are deterministic. A stochastic model with reciprocal effects between variables may be specified as follows:

$$dY/dt = a_1 + \alpha_1 X(t) + \alpha_2 Y(t) + \theta_y(t) \qquad (4.1)$$

where $\theta(t)$ is a Brownian stochastic process (cf Karlin & Taylor, 1981); the integral of a Brownian process is normally distributed with zero autocorrlation over non-zero time lags. Maximum likelihood (ML) estimation of the parameters of the model in equations 4, assuming multivariate normality of all variables in the model, is described in Arminger (1986). Software for estimation is given in MacKinnon, Dwyer and Arminger (1988).

3. An example: Blood pressure and relative weight in Framingham

As an example of the application of stochastic differential equation models to epidemiologic data, equations 4.1 and 4.2 were fit to SBP and RW from the Framingham Study. Measurements from exams 3 through 8 for men aged 43 to 55 at exam 8 were included (N=810). Non-sampling measurement error in SBP was estimated by using the two measures at each exam as multiple indicators of a latent variable (cf Dwyer, 1983). Metropolitan relative weight was used as the measure of relative weight. Systolic blood pressure was presumed to be first order autoregressive with a "random effect" that varied across individuals but not across examinations. Relative weight was presumed to be first order autoregressive. The fit of the model with the data was only moderate (chi-square/degrees of freedom = 343/127), suggesting that additional or alternative parameters could be added to the model.

The parameter estimates based upon this model, with standard errors in parentheses, were as follows:

$$\hat{\alpha}_1 = .25(.04) \qquad \hat{\alpha}_2 = -.87(.09)$$

$$\hat{\beta}_1 = -.03(.01) \qquad \hat{\beta}_2 = -.041(.007)$$

The intriguing finding here is that the coefficient relating level of RW to rate of change in SBP (α_1) is positive and sizable relative to its standard error. In contrast, the coefficent reflecting the relationship between level of SBP and rate of change in RW (β_1) is actually negative and close to zero.

These results do not demonstrate that RW is a cause of SBP. However, they do indicate that level of RW predicts change in SBP, while level of SBP does not predict subsequent change in RW. And they are consistent with a model in which an exogenously determined increase in RW leads to a subsequent rise in SBP, but an exogenously determined increase in SBP does not lead to an increase in RW. The time path of the SBP response to a change in RW can be specified using the estimated parameters of the model. (Note that the units of the variables have been standardized by subtracting the respective exam mean and dividing by the baseline exam standard deviation. This parameterization retains all

time.)

4. Concluding remarks

The results of the analysis of data from Framingham are encouraging since they yield plausible results. However, the analyses presented are for only a small segment of the Framingham population, and the hypothesized model evidenced only a moderate fit with the data. Thus, the use of stochastic differential equation models to investigate the temporal relationship of changes in continuous variables is a promising avenue for further research.

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REGRESSION ANALYSIS WITH LONGITUDINAL DATA

Scott L. Zeger, Johns Hopkins University

1. Introduction

A longitudinal data set is comprised of repeated observations on each of many subjects. For each subject ($i=1,..,K$) we observe an outcome variable, y_{it}, and a set of p predictor variables or covariates, $x_{it} = (x_{it,1},..,x_{it,p})'$ at times $t=1,..,n_i$. Most scientific questions can be formulated in terms of the dependence of y_{it} on x_{it}. The objective of analysis is therefore to describe y_{it} as a simple function of x_{it}. We'll restrict our attention to the situation where the number of observations, n_i, is small relative to the number of subjects, K. This is the case in most epidemiologic and public health studies.

An example is from the Six Cities Study (Ware, et al., 1984) in which mother's cigarette smoking was examined as a risk factor for children's respiratory infection. The outcome is the presence/absence of respiratory infection. The predictor variables include mother's smoking status, the child's age, race and sex. Observations were made for four consecutive years on several hundred children. The objective is to determine whether respiratory infection is more prevalent among children with smoking mothers controlling for confounding factors. See Laird, Beck and Ware (1986) or Zeger, Liang and Albert (1986) for more details.

With a single observation per subject, regression methods to describe the dependence of y_{it} on x_{it} are well developed. A variety of discrete and continuous outcomes can be analyzed using a generalized linear model (McCullagh and Nelder, 1983) including linear, log-linear, logistic, probit, proportional odds and some proportional hazards models. In the example above, logistic or probit regression is appropriate. With longitudinal data, the repeated observations per subject are likely to be correlated violating a fundamental assumption of regression. This time-dependence must be taken into account to correctly characterize the dependence of an outcome on predictor variables.

In this paper, we discuss simple models for regression with longitudinal data. It is assumed that the dependence of y_{it} on x_{it} is the scientific focus rather than the association among repeated y's for a given subject. In Section 2, linear models are discussed. We begin by asking what happens if the correlation is ignored. A simple approach to accounting for correlation is then introduced. Section 3 considers extensions of generalized linear models for longitudinal data. We briefly distinguish between three approaches: marginal, transitional and random-effects models.

2. Linear Models

The linear model can be written

$$y_{it} = x_{it}'\beta + \epsilon_{it}, \quad \begin{array}{l} t = 1,..,n_i \\ i = 1,..,K \end{array}$$

where ϵ_{it} is a random error with mean 0 and variance σ^2. In the longitudinal data context, ϵ_{is} and ϵ_{it} are correlated. Let $\epsilon_i = (\epsilon_{i1},..,\epsilon_{in_i})$ and $\text{cov}(\epsilon_i) = \Sigma_i$ so that $\text{cov}(\epsilon_{is}, \epsilon_{it})$ is the s,t element of the $n_i x n_i$ matrix Σ_i.

A natural (and self-serving) question to begin with is what is the effect of ignoring correlation in linear regression for longitudinal studies. That is, why not simply assume $\text{cov}(\epsilon_{is}, \epsilon_{it}) = 0$. The obvious motivation is that under this assumption standard linear regression can be used. We'll refer to this approach as the "ostrich analysis" since our head is in the sand with respect to correlation. The specific answer depends on the study design, degree of correlation and other factors. However, two rules of thumb are valid in most cases of practical interest:

[1] regression coefficients obtained when correlation is ignored, call them $\hat{\beta}_I$ (I for "independence"), are unbiased and are nearly as good as the best which we'll call $\hat{\beta}$;

[2] variance estimates for $\hat{\beta}_I$ obtained when correlation is ignored, $\hat{V}_I$, can be grossly incorrect.

These rules of thumb can be illustrated with two simple examples. The first is a linear model for a study comparing the mean response in two groups of equal size, K/2. Let $x_i = 1$ if a subject is in Group A and $x_i = 0$ if he is in Group B. A model for estimating the difference between the two groups using repeated observations on each subject is

$$y_{it} = \alpha + \beta x_i + \epsilon_{it} \quad .$$

The second example is a model for trend. We assume each subject's outcome changes according to the same linear function of time:

$$y_{it} = \alpha + \beta t + \epsilon_{it} \; .$$

In each example, we suppose $\text{corr}(\epsilon_{is}, \epsilon_{it}) = \rho^{|s-t|}$. Table 1 presents the ratio of the variance of $\hat{\beta}_I$ to the variance for $\hat{\beta}$, the best possible estimator for the case $n = 5$, $\rho = 0.0$, 0.4 and 0.8 and $K \to \infty$. Even when $\rho = 0.8$ and neighboring observations are highly correlated, ignoring the correlation costs little in terms of study efficiency as stated in the rule of thumb [1]. Table 1 also presents the ratio of the true variance for $\hat{\beta}_I$ relative to the estimate $\hat{V}_I$ obtained when correlation is ignored. When $\rho = 0.8$ in Example 1, the variance obtained in the ostrich analysis is too small by a factor of 3.6. In the second example, $\hat{V}_I$ is too small for some values of ρ and too large for others. As with all rules of thumb, these have exceptions. Special care is required when the number of subjects is moderate (say < 150) or when the number of observations per subject is large (say > 10).

The major cost of failing to account for time-dependence is incorrect variance estimates for regression coefficients. However, when $K >> n_i$, this can be overcome by using a robust variance estimate. Let $X_i = (x_{i1},\ldots,x_{in_i})'$ be the $n_i \times p$ matrix of covariates for subject i. The incorrect variance, V_I, for $\hat{\beta}_I$ has the form

$$V_I = (\sum_{i=1}^{K} X_i'X_i)^{-1}\sigma^2 \quad .$$

The correct variance is given by

$$V_T = \text{Var}\ \hat{\beta}_I = V_I(\sum_{i=1}^{K} X_i' \ \text{cov}(\epsilon_i)X_i)\ V_I \ .$$

V_T can be estimated by replacing $\text{cov}(\epsilon_i)$ in the formula above by $(y_i - X_i\hat{\beta}_I)(y_i - X_i\hat{\beta}_I)'$ as described by Liang and Zeger (1986). This is the "robust variance" estimate. It is actually an old idea having been proposed by Cox, (1962), Huber (1967) and more recently by White (1982). The clever ostrich has its head in the sand with one eye exposed to see impending danger. The clever ostrich analysis is to use $\hat{\beta}_I$ which ignores correlation and is simple to compute in conjunction with the robust variance estimator, $\hat{V}_T$, which takes the correlation into account without computational difficulty. This approach is nearly optimal when $K >> n_i$ in most cases of practical interst.

In summary, when dependence of y_{it} on x_{it} is the scientific focus, energy should first be invested in choosing the correct regression model. Valid and nearly optimal inferences about regression coefficients can be made even when crude assumptions about the time dependence are used.

3. Generalized Linear Models (GLM's)

The linear model has a special attribute not shared by non-linear regression models. In the linear model, the interpretation of regression coefficients is the same regardless of the nature of the correlation among repeated observations. In Section 2, we've shown how valid inferences about coefficients can be made even when $\text{cov}(\epsilon_i)$ is misspecified. With non-linear models, the scientific interpretation of coefficients is inseparable from the modelling of time dependence. In this section, we briefly review GLM's for independent data and then summarize three distinct approaches to non-linear models for longitudinal data.

3.1 GLM's for Independent Data.

In the GLM, it is assumed y_i ("t" dropped for convenience) is an observation on an exponential family distribution satisfying

$$h(E(y_i)) = x_i'\beta$$

and

$$\text{var}(y_i) = g(E(y_i))\cdot\phi$$

where h and g are known "link" and "variance" functions and ϕ is a possibly unknown scalar. For a variety of functions, h and g, the same methodology can be used to estimate β. Hence, these models form the GLM class.

Examples are the most effective way to develop intuition about GLM's. In linear regression, $h(E(y_i))=E(y_i)$ and $\text{var}(y_i)=1\cdot\phi$; i.e. the linear link and constant variance functions are used. In logistic regression for binary outcomes, we assume $\text{logit}(E(y_i)) = x_i'\beta$ and $\text{var}(y_i) = E(y\ )[1-E(y_i)]$. Here $\phi = 1$. Finally, in log-linear models, $\log(E(y_i))=x_i'\beta$ and $\text{var}(y_i) = E(y_i)\phi$. Each of these is a special case in which particular link and variance functions are assumed. The same algorithm (e.g. GLIM, Baker and Nelder, 1978) can be used to fit these and many other models. See McCullagh and Nelder (1983) for a detailed development of GLM's.

3.2 Extensions of GLM's for Longitudinal Data

Three extensions of GLM's for longitudinal data analysis have been called: marginal, transitional and random-effects models (Ware, Lipsitz and Speizer, 1987). For non-linear link functions, these distinct approaches to modelling time-dependence lead to coefficients with distinct meanings. The objective of this section is to briefly introduce each approach and to distinguish among the interpretations of their coefficients.

Marginal Model: In this case, the marginal expectation or cross-sectional average Y is modelled. For example, with binary outcomes we might assume

$$\text{logit}(E(y_{it})) = x_{it}'\beta \ .$$

The parameter, β, characterizes how the cross-sectional frequency of positive response changes as a function of explanatory variables. Liang and Zeger (1986) and Zeger and Liang (1986) introduced the marginal approach to focus on the regression while treating the time dependence as a nuisance. In the GLM context, we assume $h(E(y_{it}))=x_{it}'\beta$ and $\mathrm{var}(y_{it})=g(\mu_{it})\cdot\phi$. In addition, we use a "working" correlation matrix, $R(\alpha)$, possibly depending on unknown parameters, α, to approximate the time-dependence. R is a "working" matrix because with non-Gaussian responses, the actual correlation among a subject's outcomes may depend on the mean values, $\mu_{it} = E(y_{it})$. However, it is not necessary to explicitly model the dependence of R on μ_{it} because $\hat{\beta}$ and $\hat{\mathrm{var}}(\hat{\beta})$ can be made robust to misspecification of R as is done in the linear case. We use a generalized estimation equation (GEE) approach to estimate β. It is an extension of the GLM estimating equation to multivariate responses.

To briefly describe the GEE calculations, let $A_i = \mathrm{diag}(g(\mu_{i1}),\ldots,g(\mu_{in_i}))$. Then $V_i(\alpha) = A_i^{\frac{1}{2}}R_i(\alpha)A_i^{\frac{1}{2}}\cdot\phi$ is the working covariance matrix for y_i. We define the GEE estimate of β as the solution of the generalized estimating equation (GEE)

$$U(\beta) = \sum_{i=1}^{K} \frac{\partial\mu_i'}{\partial\beta} V_i(\hat{\alpha})^{-1}(y_i - \mu_i) = 0 \qquad (3.1)$$

where $\mu_i=(\mu_{i1},\ldots,\mu_{in_i})'$ and $\hat{\alpha}$ is a consistent estimate of α. Equation (3.1) reduces to the least squares equations when $h(\mu_{it}) = \mu_{it}$.

The form of (3.1) was chosen so that the inferences about the regression coefficients, $\hat{\beta}$, are insensitive to incorrect choice of the working covariance matrix, V_i, which involves both $g(\mu_{it})$ and R. The strategy is to only use information in the first sample moment to estimate β. We use information in the second sample moment to weight the data efficiently. For non-Gaussian outcomes, there is information about β in second and higher moments. To use it, however, one must run the risk of biased estimates of β when the assumptions about the time dependence are incorrect.

The variance of $\hat{\beta}$ is given by

$$\mathrm{var}(\hat{\beta}) = M_0^{-1}M_1M_0^{-1}$$

where

$$M_0 = \sum_{i=1}^{K} \frac{\partial\mu_i'}{\partial\beta} V_i^{-1} \frac{\partial\mu_i}{\partial\beta} \qquad (3.2)$$

$$M_1 = \sum_{i=1}^{K} \frac{\partial\mu_i'}{\partial\beta} V_i^{-1}(y_i - \mu_i)(y_i - \mu_i)'V_i^{-1} \frac{\partial\mu_i}{\partial\beta} \quad .$$

This is a consistent estimate even when $\mathrm{var}(y_{it}) \neq g(\mu_{it})\cdot\phi$ or R is not the correlation matrix of y_i.

If we choose $R_i(\alpha) = I$, that is we adopt the working assumption that repeated observations are uncorrelated, solving the GEE (3.1) is the same as fitting the usual (linear, logistic, probit, log-linear) regression models for independent data. Hence, available software can be used. However, the correct variance for $\hat{\beta}$ is given by (3.2) and is not supplied in most commercial software. Using $\hat{\beta}$ and the robust variance in (3.2) is the extension of the clever ostrich analysis for GLM's.

Transitional Models: In transitional models (Ware, Lipsitz and Speitzer, 1987), the conditional expectation of y_{it} given the past $D_{it} = (y_{it-1},\ldots,y_{i1})$ is assumed to depend on x_{it} and on past values. For example, with binary outcomes the model

$$\mathrm{logit}(E(y_{it}|D_{it})) = x_{it}'\beta + \theta y_{it-1} \qquad (3.3)$$

was proposed by Cox (1970) and used by Korn and Whittemore (1979) in an analysis of respiratory disease and air pollution. The parameter, β, characterizes the dependence on X of the transition probabilities in a Markov chain. In the logit model for respiratory infection introduced in Section 1, the mothers' smoking coefficient in (3.3) would be the log odds of respiratory infection at time t given infection (or not) at time t-1 for children whose mothers smoked relative to children whose mothers did not smoke. Zeger and Qaqish (1986) have proposed a generalization of (3.3). Letting $u_{it} = E(y_{it}|D_{it})$, we assume

$$h(u_{it}) = x_{it}'\beta + \sum_{u=1}^{q} \theta_u f_u(D_{it}) \qquad (3.4)$$

where h is a known link function, f_u's are known functions of the past, and β and θ are unknown parameters to be estimated from the data. The parameters, β, are of primary scientific interest as they characterize the dependence of the outcome on risk factors. (3.3) is a special case of (3.4) with a logit link function and $f_u \equiv y_{it-u}$. Autoregressive models for Gaussian data also satisfy (3.4).

Random-effects models: Here, the conditional distribution of a response given a random effect, b_i, is assumed to satisfy

$$h\big(E(y_{it}|b_i)\big) = x_{it}'\beta + z_{it}'b_i \qquad (3.5)$$

and

$$\mathrm{var}(y_{it}|b_i) = g\big(E(y_{it}|b_i)\big)\cdot\phi \ .$$

The z_{it}'s are a subset of the covariates, x_{it}; the fixed effects parameters, β, describe the dependence on X of a typical subject's response; and b_i is the deviation of the coefficients for subject i from β. For the logistic link, a coefficient in β is the log odds ratio of the response given an individual changes his or her X by one unit. This is in contrast to the coefficient in a marginal model which is a population-averaged statistic (Zeger, Liang and Albert, 1986). The random effects, b_i, are assumed by most investigators to be Gaussian with mean 0 and unknown variance, D. The goal of inference is to estimate β and D and often the random-effects, b_i.

The random-effects generalized linear model has recently received attention by several authors (e.g. Stiratelli, Laird and Ware, 1984; Anderson and Aitkin, 1985; Gilmore, Anderson and Rae, 1985; Zeger, Liang and Albert, 1986). Methods for estimating the fixed effects, β, are reasonably well developed; estimates of the random effects distribution and of $\mathrm{var}(\hat{\beta})$ are not.

In summary, we have introduced three distinct extensions of GLM's for the analysis of longitudinal data. The regression coefficients in these models have distinct interpretations except in the linear model. The choice of model must be guided by the scientific focus of the data analysis.

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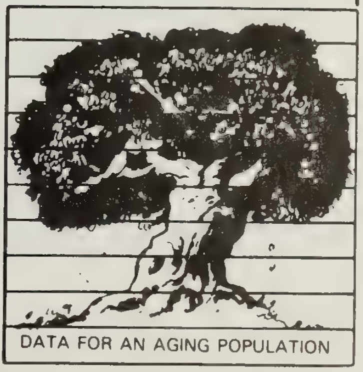
Table 1. Relative efficiency, $E = \hat{Var}(\beta_I)/\hat{Var}(\hat{\beta})$, of the estimator $\hat{\beta}_I$ obtained by ignoring correlation relative to the best possible, $\hat{\beta}$; and the variance inflation factor, $R = Var(\hat{\beta}_I)/V_I$, where V_I is the variance when repeated observations are independent, for two models: I. $y_{it} = \alpha + \beta x_i + \epsilon_{it}$, $x_i = 1$ or 0; II. $y_{it} = \alpha + \beta t + \epsilon_{it}$. In both models, ϵ_{is} and ϵ_{it} have correlation $\rho^{|s-t|}$, $n_i = 5$ and $K \to \infty$.

	Example I		Example II	
ρ	E	R	E	R
0.0	1.00	1.00	1.00	1.00
0.4	1.03	1.90	1.03	1.22
0.8	1.05	3.62	1.05	0.78

Session F

Long-Term Health Care



DATA FOR AN AGING POPULATION

NATIONAL LONG-TERM CARE CHANNELING DEMONSTRATION PROGRAM

Mary Harahan, Department of Health & Human Services

The U.S. Department of Health and Human Services (DHHS), in recognition of the large and rapidly growing need for long-term care for the functionally impaired elderly, funded a major demonstration to test the feasibility and cost-effectiveness of comprehensive case management and community-based long-term care service delivery as an alternative to the existing long-term care services system.

Ten community projects in ten different States participated in the National Long-Term Care Channeling Demonstration. Participating States were Florida, Kentucky, Maine, Maryland, Massachusetts, New Jersey, New York, Ohio, Pennsylvania, and Texas.

PROGRAM PLANNING AND MANAGEMENT

The Channeling demonstration was an intradepartmental long-term care initiative funded by the Health Care Financing Administration (HCFA), the Administration on Aging (AoA), and the Office of the Assistant Secretary for Planning and Evaluation (ASPE).

Planning for the Channeling demonstration began at the Federal level in 1978. In fiscal year 1980, Congress appropriated $20 million for a long-term care initiative to be designed and implemented by three groups within DHHS. The Federal planning efforts culminated in the issuance in April of 1980 of a request for proposals from States interested in operating a Channeling project. The States, a technical assistance contractor, and an evaluation contractor were selected in September of 1980.

DHHS had overall responsibility for the demonstration. The technical assistance and evaluation contractors had demonstration-wide responsibilities carried out under DHHS' direction. The fact that these activities were all demonstration-wide was crucial to the establishment of uniform procedures across sites, the commitment of State and site staff to the evaluation objectives of the demonstration, and the faithfulness of program operators to the operational procedures imposed on them by the research requirements.

DHHS announced the selection of 12 States in September of 1980: Florida, Hawaii, Kentucky, Maine, Maryland, Massachusetts, Missouri, New Jersey, New York, Ohio, Pennsylvania, and Texas. (Hawaii and Missouri were later dropped for budgeting reasons from the group of research sites included in the national evaluation of Channeling, although they continued to operate their Channeling programs.)

OVERVIEW

Channeling was the provision of case management and community-based long-term care services to people 65 and older who were functionally impaired and unable to manage the essential activities of daily living (ADL) on their own, and who lacked adequate informal supports. The specific goal was to enable impaired elderly persons to stay in their own homes rather than entering nursing homes whenever possible, and in this way control overall long-term care costs.

Two models of Channeling were tested in the demonstration: a Basic Case Management Model and a Financial Control Model (or Complex Model).

DESCRIPTION OF CHANNELING MODELS

The Basic Case Management Model superimposed a coordinating and accountability mechanism -- case management -- onto the present system of services and client eligibilities. It accepted the features of the present long-term care system as given and introduced a mechanism responsible for helping clients gain access to and coordinate the services they need to continue to live in the community. The Channeling organization assigned to each client a case manager, who performed a comprehensive assessment of service needs; developed a plan of care that responded to those needs; arranged for the provision of needed services, relying on family and friends where feasible; followed up to see that they are provided and monitored their provision on an ongoing basis; and reassessed needs periodically or when circumstances changed. Thus, the case manager was accountable for identifying the entire package of services needed by the client and served as a client advocate in negotiating the complex array of programs and service providers.

The Basic Case Management Model, therefore, tested the premise that the major difficulties in the current long-term care system are problems of information, access, and coordination, which can be essentially solved by client-centered case management.

The Financial Control Model (or Complex Model) modified the Basic Model to control costs and to strengthen the projects' ability to access needed services. Projects were provided with fixed budgets, set at 60 percent of the average Medicaid Skilled Nursing Facility/Intermediate Care Facility (SNF/ICF) rate in the catchment areas, designed to help gain control over rising costs and increased demand for long-term care services. Federal and State waivers provided reimbursement for a variety of services that offered clients and care planners the opportunity to design more appropriate and efficient care plans than is generally possible under the current fragmented system of categorical programs. Services for which coverage was extended included:

- Day Health and Rehabilitative Care
- Day Maintenance Care
- Home Health Aide Services
- Homemaker/Personal Care Services
- Housekeeping Services
- Chore Services
- Companion Service
- Home Delivered Meals
- Respite Care
- Skilled Nursing
- Physical Therapy
- Speech Therapy
- Occupational Therapy
- Mental Health Services
- Housing Assistance
- Adult Foster Care
- Nonroutine Consumable Medical Supplies
- Adaptive and Assistive Equipment

These services were paid for from a pool of service dollars primarily comprising Medicare and Medicaid funds, made available through waivers of some requirements of those programs. Services reimbursed out of the services pool were not dependent on a client's eligibility for particular categorical programs. Case managers had the power to authorize the amount, duration, and scope of services paid for from the funding pool. This vested in the case manager the power to limit, alter, or terminate services in response to changes in client needs. The power to authorize community-based services, irrespective of funding source, enhanced the case manager's ability to obtain services and control the cost of care plans, making the case manager accountable for the full package of services funded. In addition, clients whose income was above a protected amount (200 percent of SSI, plus State supplement, plus food stamp bonus) were required to share in the cost of services for which they would be subject to an income test outside of Channeling.

CORE FUNCTIONS

Both the Basic and the Complex Model included the following core clinical functions.

1. Screen. The process during which information was collected and recorded on the screen instrument, and a preliminary

determination made whether an applicant was appropriate for the demonstration by comparing that information to standard selection criteria. The information needed for this comparison included age and nature of the applicant's problems, available formal and informal supports, extent of unmet needs, the probable duration of the needed care, and performance on ADL's (activities of daily living) and IADL's (instrumental activities of daily living).

2. Assessment. The collection of in-depth information about a person's situation and functioning which allows identification of the person's problems in the major functional areas, and permits the development of a plan of care. The Baseline Assessment Instrument was used both for research and clinical purposes.

3. Care Planning. The process of developing an agreement between client and worker regarding client problems identified, outcomes to be achieved, and services to be provided in support of goal achievement.

4. Arranging for Services. The process of negotiating with service providers, including formal and informal resources, for the delivery of needed services to the client in the manner described in the care plan.

5. Follow-up and Monitoring. The continuing contact the case manager has with providers and clients to ensure that services are being provided in accordance with the care plan and to ascertain whether these services continue to meet the client's needs.

6. Reassessment. The scheduled or event-precipitated re-examination of the client's situation and functioning to identify changes which occurred since the initial or most recent assessment and to measure progress toward the desired outcomes outlined in the care plan.

CASE MANAGEMENT

The case manager assessed need, developed a plan of care, coordinated and arranged for services, monitored services provision, reassessed need and revised care plan as the client's condition changed, and served as the client's advocate.

There were several factors involved in Channeling case management:

1. The Population. The clients were frail, vulnerable, severely impaired, often isolated, in need of long-term care services for an extended period of time, and in the absence of Channeling, were at high risk of being institutionalized.

2. Cost Consciousness. The case managers, usually social workers and nurses, followed procedures that maintained awareness, and allowed control, of the costs of services that comprised plans of care.

3. Work with Informal Supports. The case manager worked with the family, family members, and other informal supports in order to arrange for formal providers to augment what the informal support system was capable of doing.

4. Health and Social Services. The case manager attempted to establish a new set of relationships between health and social service providers to substitute services provided in the community -- both formal and informal -- for institutional care, wherever community care is appropriate.

THE TECHNICAL ASSISTANCE CONTRACT

The technical assistance contractor for the Channeling demonstration was Temple University. Major responsibilities included: training screeners, assessors and case managers; responding to the needs of the sites; maintaining the communication network; assisting the government on program issues; and conducting an exploratory study of care planning. A number of program-related materials were developed during the planning and implementation of Channeling. The DHHS contract with Temple University ran from September 30, 1980 through December 1985.

THE EVALUATION

Mathematica Policy Research, Inc. (MPR), under contract to DHHS was responsible for evaluating the demonstration. This included the development of the research design, data collection instruments and procedures, the collection of the data and the performance of the analysis. MPR is an independent policy research and evaluation firm based in Plainsboro, New Jersey.

The evaluation employed a randomized experimental design to compare what happens under the demonstration with what would have happened in its absence. Applicants judged appropriate for the demonstration, based on a functional impairment screen, were randomly assigned to either a client or a control group. This permitted a direct comparison of the impact of the demonstration on participants with the outcomes of the control group members who received their services through the conventional delivery system. Participants in the research, both clients and controls, received comprehensive initial and follow-up interviews designed to gather data about their health, quality of life, use of formal and informal services, and expenditures for services. Additional information on costs and use of formal services were obtained from Medicare/Medicaid records and service provider interviews with informal caregivers. The evaluation also included an analysis of the actual implementation experience of the project, its relation to the existing service delivery system, its costs and its clientele. This analysis was based on interviews with key provider and project staff in the demonstration communities, as well as on data from the instruments used in the impact analysis, project reports, and existing public and project documentation.

All data collection activities involving information about individuals were reviewed and approved by MPR's Institutional Review Board established for protection of human subjects involved in research. All data about individuals remain confidential. Individuals who agreed to participate in the demonstration and research signed an informed consent, as well as releases for access to their records. Data collection forms and instruments were reviewed and approved by the U.S. Office of Management and Budget, and they, along with the project's record-keeping system, have received clearance under the Federal Privacy Act. The DHHS contract with MPR, Inc. ran from September 30, 1980 through June 30, 1986.

MAJOR DATA COLLECTION ACTIVITIES

- Screening data on all appropriate applicants.
- Baseline and two 6 month follow-ups on full sample of treatments and controls. 18 month follow-up on half the sample.
- Medicaid and Medicare claims data on full sample.
- Extracts from provider billing records of services utilized by a 20 percent subsample of treatments and controls.
- Baseline validation interviews by MPR interviewers of about 400 treatment group members.

- Check of death records for sample members who do not have a completed follow-up interview.

- Baseline and two 6 month follow-up interviews with primary informal caregivers for a subsample of late enrollees.

- Process analysis interviews with staff of States, sites, Temple University, and DHHS.

- Channeling project cost and caseload reports.

MAJOR FINDINGS

Major findings from the demonstration include the following:

- The population served by Channeling was extremely frail, had low incomes and reported many unmet needs. The average age was 80 years, the average income was $542 a month and 84 percent were restricted in their ability to perform ADL. The remainder, while having no ADL impairments, had multiple impairments with respect to the IADL. A large majority of respondents (82.5 percent) reported their overall health as fair or poor.

- A high proportion of the Channeling sample was female (70.8 percent). Slightly more than 30 percent were married at the time of their baseline interview. With respect to ethnicity, blacks constituted approximately 24 percent of the sample while Hispanics comprised approximately 4.5 percent. Over one-third of the sample members (37 percent) lived alone and 47 percent had been hospitalized in the two months prior to enrollment in Channeling.

- Channeling's comprehensive case management services were implemented largely according to plan for the treatment group, but a substantial minority of the control group also received case management from other sources.

- Channeling substantially increased the receipt of formal community services; this increase was particularly noteworthy in the Financial Control Model.

- Despite the increase in case management and formal community services, Channeling did not affect hospital use under either model. For example, at the end of the twelfth month after the baseline interview, 3.6 percent of the treatment group and 4.1 percent of the control group in the Basic Model were in a hospital. For the Financial Control Model, 6.2 percent of the treatment group and 5.1 percent of the control group were in a hospital. The treatment-control differences in all cases are not statistically significant.

- Channeling did not affect nursing home use under either model. At the end of the twelfth month after baseline, 11.5 percent of the treatment group and 12.6 percent of the control group in the Basic Model were in a nursing home. For the Financial Control Model, 11.3 percent of the treatment group and 13.5 percent of the control group were in a nursing home. There differences are not statistically significant.

- Channeling did not have a significant effect on the longevity of the sample members under either model. The mortality rate for the sample was about 17 percent 6 months after random assignment, 27 percent after 12 months and 36 percent after 18 months. There were no statistically significant differences observed between treatment group and control group members.

- There is no evidence that Channeling led to substitution of formal for informal care in the Basic Case Management Model. There was evidence of some substitution in the Financial Control Model. However, it resulted from reductions in caregiving by some friends and neighbors rather than primary caregivers such as spouses or daughters.

- Channeling led to an increase in the total subsistence, medical and long-term care costs per client over the 18 month observation period. The Basic Case Management Model appeared to increase these costs by about $1500 per client or approximately 8 percent above the $18,000 in costs that would be expected without Channeling. In the Financial Control Model, the cost increase was $3500 or 16 percent over the $23,000 that would otherwise be expected.

- Public expenditures for subsistence, medical treatment and long-term care services for the first 18 months after enrollment increased under both models. In the Basic Model, government costs rose by 10 percent (approximately $1900 per client) and in the Financial Control Model by 17 percent ($3900) per client. These increases were due mostly to the costs of Channeling case management and for the extra formal community services arranged by Channeling.

- Channeling improved the well-being of caregivers by some measures, especially in terms of satisfaction with care arrangements and overall life satisfaction.

- Channeling reduced reported unmet needs, increased confidence in receiving needed services and increased satisfaction with service arrangements for clients. There were small but generally beneficial effects on social and psychological well-being.

PATIENT CHARACTERISTICS OF ELDERLY PERSONS WHO RECEIVE MENTAL HEALTH SERVICES

Marilyn J. Rosenstein, Ronald W. Manderscheid,
Laura J. Milazzo-Sayre, and Robin L. MacAskill
National Institute of Mental Health

ABSTRACT

This paper is based on the most recent national data on the use of inpatient psychiatric services by persons age 65 and over. Four surveys were conducted in 1980 by the Survey and Reports Branch, NIMH, and sampled admissions to the inpatient psychiatric services of State and county mental hospitals, private psychiatric hospitals, and Veterans Administration medical centers (VAMCs), and discharges from the separate inpatient psychiatric services of non-Federal general hospitals. This paper examines the sociodemographic, clinical, and treatment characteristics of persons age 65 and over admitted to these inpatient psychiatric services. Specifically, the following characteristics are discussed: age, sex, race, marital status, diagnosis, prior mental health care, type of treatment, and median length of stay.

Persons 65 years and over accounted for 7 percent (99,715) of the 1.3 million admissions to these four types of inpatient psychiatric services in 1980 with an admission rate of 388 per 100,000 U.S. civilian population. Of this elderly inpatient population, 59 percent were admitted to non-Federal general hospitals; 20 percent, to State and county mental hospitals; 14 percent, to private psychiatric hospitals; and 7 percent, to VAMCs. Overall, 90 percent of elderly admissions were white; 55 percent, female; and 67 percent, between ages 65 and 74.

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USE OF FORMAL AND INFORMAL SERVICES IN COMMUNITY-BASED LONG TERM CARE

Karen S. Harlow, Purdue University Fort Wayne; Laura B. Wilson, University of Maryland College Park; Mark S. Rosentraub, Indiana University Fort Wayne.

1.0 RESEARCH ISSUES AND FOCUS OF REPORT

Health policy specialists generally agree that the DRG-based Prospective Payment System has contributed to decreasing lengths of stay in acute care hospitals with the corresponding result of discharge of elderly patients into the community or transitional care in a more vulnerable state (GAO, 1986a; GAO, 1986b). For example, in 1984, the percentage of times hospitals discharged Medicare patients to skilled nursing homes, intermediate care facilities and home health agencies was 2.5 to 3 times higher for PPS hospitals than for non-PPS hospitals (HHS/HCFA, 1986). Discharge planners report increasing difficulty in finding appropriate post-hospital placement and services (GAO, 1987). If the DRG reimbursement system results in quicker and sicker discharges, what happens to the community-based service structure which may be overloaded and incapable of responding to increased demands or to the changing nature of service needs?

One possible response is the substitution of informal or free services for needed skilled services. National surveys have indicated that a large majority of assistance to dependent elders is provided within the family or informal structure. Specifically, informal caregivers are more likely to provide assistance with instrumental activities of daily living such as grocery shopping and chores than with assistance in bathing, eating or toileting. As the need for assistance in more personal activities of daily living such as dressing or bathing increases, families and friends rely more on formal services for the dependent elder when these are accessible or available (Kane and Kane, 1986).

This paper explores the reliance upon informal and formal service providers for a typology of different services and the implications for these service delivery decisions and choices upon specific targeted populations of elders. In this analysis, the long term care service structure is divided into a paradigm of services based on the site of service delivery (home vs. community) and the level of skill necessary to perform the service. In-home health and personal care services include in-home skilled nursing services or therapies, or services which involve close personal interaction with the dependent elder such as assistance in dressing, bathing, feeding or toileting. Chore services delivered in the home include the types of assistance which are less likely to require technical, health-related skills. For example, assistance in light housekeeping, cooking, heavy cleaning, laundry, grocery shopping, using the telephone, and maintaining checking accounts or managing business affairs require non-health related skills. Services delivered in the community include meals assistance outside the home, case management, mental health counseling, nursing home services, respite care outside the home, adult day care, educational programs for nutritional or health needs, legal assistance, occupational or career counseling and senior center activities.

This report will profile this paradigm of services in four sites from Wave I of the National Panel Study of Health and Aging (NPSHA). The report will detail the pattern for use and need for services in the following categories:

In-home health/personal care
Formal, paid   Informal
Need one or more
In-home Chore
Formal, paid   Informal
Need one or more
Community Services
Use Now   Need Now

From this analysis, categories of service mix or unmet need mix within the health and personal care categories and the in-home chore services will be detailed. Finally, all service categories are collapsed into two composite variables to identify use and need mixes across the three broad service types. For each of these variables, analyses are presented for each of the four sites representing differing locales as well as different types of service structures.

2.0 LONG TERM CARE AND IDENTIFICATION OF NEED

An understanding of the utilization of long term care services is somewhat easier to identify than is an understanding of unmet needs for services. A variety of different sources may be accessed to identify users including service provider records and reimbursement records from Medicare, Medicaid or other insurance records or consumers themselves. The concept of unmet need is far more difficult to accurately measure. Reliance on actual service use can misrepresent the level of need in a community where problems in accessibility or lack of availability can influence calculations of need (Kane and Kane, 1986). Limitation in functional abilities is generally accepted as one of the most appropriate measures of need for services. Some adaptation of measures in functional limitation are utilized in most of the major national health-related studies and in several of the state and local studies which address this issue (Branch, 1977; Branch and Jette, 1981; Weissert, 1982; Scanlon and Hamcke, 1983; Manton and Soldo, 1985; Harlow and Wilson, 1987; Ramsdell, Harlow and Wilson, 1987). The National Panel Study on Health and Aging (Harlow and Wilson, 1986) follows this protocol by identifying 15 activities of daily living and instrumental activities of daily living and analyzing individuals who have limitations and 1)receive no help; 2)receive informal, unpaid help; 3)receive formal, paid help; or 4)use a combination of formal and informal services for a specific limitation.

Among these three broad categories of home health and personal care, chore services and community services, the one service area which is currently receiving the most attention from Congress is home health. The Medicare benefit for home health care is narrowly defined. These benefits are, by law, oriented toward skilled nursing care. They were not designed to provide services for individuals who have limitations with activities in daily living unless the individual also requires skilled nursing or therapy (GAO, 1986c). The Medicare manual defines the primary function of a home health aid as personal care of a patient with this care including assistance in the activities of daily living such as bathing, transfer to and from bed, grooming, exercise and assistance in taking medication. These aides are allowed to perform certain household service such as light housekeeping, laundry and meal preparation if these services are "incidental" and do not "substantially increase" the length of the aide visit (GAO, 1986c). When services are not available or financial assistance cannot be obtained due to the narrow definition, family and friends must assume the burden of care or the elder may not receive any assistance at all. Under the prospective payment system and earlier hospital discharge, this pattern may mean substantial numbers of elders are receiving no care at all or that care which requires some level of medical skill is provided by an unskilled family member(s). This pattern would create concerns about quality of services for the dependent elder and inappropriate burden and stress for families.

Policy makers must now address the changing long term care environment and the increasing size of a target population by developing an appropriate service structure with adequate and equitable reimbursement strategies. The following sections describe a data base which was developed in consultation with U.S. Senate and House Committees on Aging, AARP, National Association of Area Agencies on Aging, National Association of State Units on Aging, selected State Units on Aging and many other groups to assist decision makers in these areas.

3.0 RESEARCH SITES AND SAMPLES

To date, sites in seven states are participating in the National Panel Study on Health and Aging. This paper focuses on the first four sites in the project. Dallas/Tarrant Counties, Texas, represent a heavily urbanized, Sunbelt site in a state which traditionally de-emphasizes social services and is currently experiencing critical budgetary problems due to the drop in oil revenues. Hampden County, Massachusetts (Springfield), was selected since Massachusetts was originally one of four DRG waivered states and it has a long history of commitment to a strong and well-financed service sector, even though some tax revolt behavior has been evident (Harlow and Rosentraub, 1986).

The Arkansas sample consists of eight separate samples representing each Area Agency on Aging planning area in the state. In this study, data from each of the eight sample areas are combined for state level analysis. The State of Maryland, the fourth site in the NPSHA, represents the only site which is not under a DRG-based prospective payment system. The Maryland sample consists of five samples representing each of the five health planning regions and a sixth sample from Baltimore City. Each separate sample is combined and weighted according to its proportion in Maryland's population to produce the state level figures.

Each state represents a different type of political and social service climate which impacts the type of services offered as well as the availability and access to needed services. Although the samples are geographically dispersed, the state samples are not combined into a file which is nationally representative. The samples are analyzed as separate case studies, representative at the state or local level. The Dallas/Tarrant samples may be generalizable to other urban counties in Texas, but they do not represent the situation for rural Texas elders. Hampden County has population density, racial and poverty level characteristics similar to the State of Massachusetts. However, the sample was selected to represent the county only, and no claims for generalizability to the State as a whole are made.

Data reported in this study are gathered from a subset of randomly selected elders 65 or older in each or the four sites. Comparing across the sites, the Arkansas sample represents the site with the largest concentration of the oldest old, 80 years or older. Arkansas, Maryland and Texas sites each have comparable percentages of non-white elders in the sample with the Hampden County site reporting a substantially smaller percentage of non-whites. In both Arkansas and Maryland, the non-white population is comprised predominantly of Blacks, but in Texas, elders who describe themselves as Hispanic are included in this non-white category. (In Texas, the probe used the locally more accepted terms of Anglo and Hispanic rather than non-white).

The distribution of sexes in each of the sites reflects the longer life expectancy of females and compares favorably to the sex composition reported by the Census for each of these areas. The Arkansas repondents represent by far the largest concentration of low income elders in any of the sites. Almost two-fifths of the elders report household incomes under $7,000. Although Texas elders comprise the second largest percentage of low income elders, they also represent the largest concentration of elders earning above $15,000. The differences between Maryland, Massachusetts and Texas are not appreciable in this category, however. Also reflecting the older average age of the Arkansas sample, elders in this state were more likely to live alone than was true in the other sites.

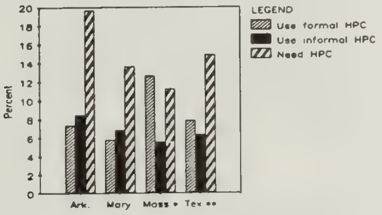
When the number of ADL/IADL impairments across sites is compared, the Massachusetts repondents appear to be substantially less impaired than respondents in the other states. Reflecting their older average age, Arkansas respondents report almost double the percentage of four or more problems than is true for the Massachusetts respondents. The Massachusetts respondents appear to be more likely to be free of chronic disease impairments, 22.7%, than is true in other states although Maryland and Texas prevalence rates are similar to national figures. Almost one in three Arkansas respondents reports four or more chronic diseases.

4.0 USE OF AND NEED FOR COMMUNITY-BASED CARE

4.1 Home Health and Personal Care

Figure 1 compares the use of formal and informal services and mix of service packages across the four sites. The first dependent variable illustrated in the chart is the use of one or more formal, in-home health or personal care services. Although Arkansas respondents reported more ADL limitations and chronic disease impairments which would lead to service utilization, Hampden County residents report substantially higher utilization rates than the other sites. This finding is important because based on demographic characteristics one would have predicted Arkansas to be the largest consumer of health and personal care services. The higher utilization rate in Massachusetts may reflect the better funded home health service structure which has evolved in this state.

Figure 1
USE OF AND NEED FOR FORMAL AND INFORMAL HEALTH AND PERSONAL CARE SERVICES: ELDERS 65 AND OLDER



•Hapmpden Co ••Dallas/Tarrant

The second variable describes the use of one or more informal home health or personal care services. This variable is particularly important because these HPC services represent a more skilled service component, and individuals who are substituting informal for formal care may be sacrificing quality of services. The comparisons across sites indicate very little variation for use of at least one informal service in this category. Although the Massachusetts respondents report the lowest percentage of informal service use, 5.6%, the upper range from Arkansas repondents is 8.5%.

The third variable calculated is need for at least one or more in-home health or personal care services. This variable represents individuals who indicate they have a problem in one or more of the ADL areas requiring the more skilled level of services and no one is helping them. Almost one-fifth of the Arkansas respondents report the need for one or more in-home health or personal care services. Slightly more than 11% of the Massachusetts respondents report no help in one or more of the ADL areas. **Thus, the respondents who record the highest level of involvement in the formal service sector also report the lowest level of unmet need while still indicating a level of informal involvement which does not differ substantially from the other sites.**

A cautionary note must be offered that this measure of unmet need is at best a very gross measure. In Phase I of the data collection, no attempt was made to determine whether individuals receiving formal or informal help actually needed more help, and no attempt was made to verify the appropriateness of the services delivered. Thus, unmet need here simply identifies individuals with some barrier who are receiving no formal or informal help for a particular problem. A GAO study (1986c) which attempted to determine levels of unmet need based on findings from the National Long Term Care Survey found that approximately 5% of the chronically ill elders who receive health and personal care help from family, friends, or formal sources judge this assistance to be inadequate. If these figures are correct, then an additional 5% should be added to the unmet need to correct for the lack of ability to measure need for additional services when services are already being received.

A grouped variable was developed to identify individuals who either receive formal or informal health or personal care services (HPC) or who report a problem which would require an HPC service but receive no help. In Arkansas, 975 elders from the sample of 3545, 27.5%, reported either the use of an HPC service or the need for one. Of this group, almost half, 49.1%, have needs but receive neither formal nor informal service. Almost 13% report no unmet needs with all needs being met by the informal service structure. In the Hampden Co. site, less than 24% of the elders either use or need HPC services, but the pattern of use and need is quite different from that demonstrated in Arkansas. While almost half of the 27.5% of Arkansas respondents who use or need services have unmet needs and receive no formal or informal services, less than one-third, 30.9%, of that same subgroup of Hampden Co. respondents have unmet needs with no services. One third of the respondents who need or receive services have all their needs met by the formal service structure, and an additional 12.6% have their needs met by the informal service structure. Arkansas, Maryland, and Dallas/Tarrant Co. sites are similar in the levels of unmet need and no service response, and Hampden Co. is substantially lower. The difference can be accounted for in the utilization of the formal service sector. However, in each site, the utilization of the informal service sector to meet needs is very similar.

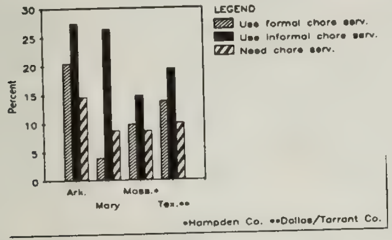
This pattern is particularly important from a policy perspective since many recommendations for modification of the service system are couched in terms of fear of a woodwork effect--if services are offered, elders will "come out of the woodwork to access them" and families will decrease their involvement in informal service provision. These early findings from Phase I would not support this contention. In the Hampden Co. site which provides a strong formal sector, one can observe from these figures that **individuals will utilize the services if available. However, it appears that families still provide substantial help even in environments with well developed, formal service systems.** These findings are consistent with Soldo's findings from the 1979 National Health Interview Survey described in Kane and Kane (1986). She found no difference in the use of informal care among those with or without formal services. Adding on of services when they are made available may occur, but it appears that **these strong service sectors may appropriately address levels of unmet need in the community, and their availability does not deter families from providing services. The very small reduction in informal participation may reflect an appropriate disengagement of families from production of services which require greater levels of skill than most possess.**

4.2 In-Home Chore Services

Most studies of informal caregiving indicate that families are most likely to provide help with the kinds of service which require less technical skill than with health or personal care. Epidemiological studies also indicate that loss of ability to perform chores such as light housekeeping, shopping and cooking may occur earlier in the chronological aging process with loss of function in dressing and feeding self representing functional disabilities which occur in later stages of aging. Prevalence rates for use of formal chore services is highest in Arkansas, 20.5%, and lowest in Maryland, 4.0%. In Hampden Co., reliance on formal chore services is 9.9%, which is a lower figure than use of formal HPC services (Figure 2). As would be expected, informal chore service provision rates are substantially higher than informal provision of HPC services in each site. In both Arkansas and Maryland, more than one-quarter of the elders receive informal assistance, and in Texas almost one-fifth report usage. In each site, levels of unmet need for chore services are actually lower than those reported for HPC. Rates vary from a high in Arkansas of 14.7% to a low in Maryland of 8.8% indicating little variation across sites. Again, one must remember that this measure of unmet need simply identifies situations where no formal or informal service response is made. The GAO (1986c) study on unmet needs indicates that 36% of the elders who are already receiving help for IADL impairments from family, friends or paid sources actually need more service. Factoring this finding into our measure would result in substantially higher projections of unmet needs.

A grouping of individuals who either use or need chore services was performed and categorized into seven groups similar to the HPC variables. The use of or need for in-home chore services was greatest in Arkansas with almost half, 45.7%, reporting either the use of formal or informal assistance or the need for assistance. Involvement with or need for chore services is lowest in Massachusetts, 26.4%. Comparison of categories across sites indicates few differences with the exception of Maryland and involvement in the formal sector. More than three-fifths, 63.5%, of the 1087 elders who use or need chore services have their needs met through informal providers. This percent is almost double the rate in the other sites. Less than 2% report their needs are met by the formal sector.

Figure 2
USE OF AND NEED FOR FORMAL AND INFORMAL IN-HOME CHORE SERVICE: ELDERS 65 AND OLDER



4.3 Community Services

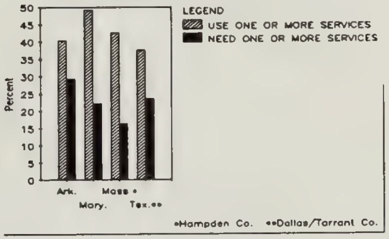
Recent findings from the 1984 Supplement on Aging to the National Health Interview Survey provide estimates of people 65 or older who report using community services during the previous year (Stone, 1986). Utilization rates were low with 21.5% reporting use of one or more services during the previous year. These findings do not take into account availability and access to services, geographic variability, ability to pay for services, or unpaid, informal care provided by family or friends.

In the NPSHA, use of community services was obtained by a different approach than that used to determine use or need for HPC or chore services. The latter technique linked service utilization or need to specific ADL/IADL problems. Because community services may respond programmatically to an array of problems, linkage to a specific disability was not possible. Respondents were asked whether or not they currently used a variety of services. Extensive effort was devoted to phrasing the service probes in understandable, "non-jargon" terms. If the elder responded that no service was used, he/she was asked if he/she needed the service. While measuring need by this technique is less than desirable, the problem of lack of familiarity with the technical service terms was largely avoided by detailed attention to the content of the probes and extensive pretesting with elders with very low educational levels.

Maryland respondents who indicate comparatively low involvement in HPC and chore services report substantially higher rates of involvement in use of community services than other sites. Reported levels of involvement range from a high of 45.2% in Maryland to a low of 23.9% in Arkansas. Even Hampden Co. with more than one-third, 36.7%, reporting involvement is substantially lower than the Maryland figures. Perception of need for service is also highest among Maryland elders with 8.5% indicating a need for one or more services. Hampden Co. reports the lowest level of need at 2.5%.

In addition to analyses of the individual service categories by formal or informal provider, two grouped variables were developed. The first variable identified the mix of formal services used and the second identified the mix of service needs. Figure 3 presents the findings by site. When combining the three formal service typologies, utilization rates range from a high in Maryland of 49.3% to a low in Dallas/Tarrant of 37.8%. Unmet need for at least one service of any type is highest in Arkansas, 29.5%, and lowest in Hampden Co., 16.5% with Dallas/Tarrant Co. and Maryland at 23.8% and 22.4%, respectively.

Figure 3
USE OF AND NEED FOR SERVICES IN FOUR SITES: NAT'L PANEL STUDY ON HEALTH AND AGING (65 YRS OR OLDER)



The content of the formal service utilization in each site is substantively different. More than four-fifths of the formal service users in Maryland, 82.7%, use community services only. Use of all three types is highest in Hampden Co, 6.9%, with Dallas/Tarrant Co. and Arkansas reporting 4.0% and 3.1% respectively, and Maryland lowest at 1.4% (Figure 4).

Again, the content of unmet need varies by site. Approximately one-third of the respondents in each site need health or personal care only. The second largest concentration is in need for chore services with responses varying from one-fifth to one-quarter needing chore only. Almost 20% of the Maryland elders need community services only with the lowest level of need in the Massachusetts site, 5.2%.

These variations among sites illustrate some of the difficulties in developing national policy guidelines in terms of national rates while still considering the wide range of service provision and service needs among states and counties.

5.0 CONCLUSIONS

The findings detailed in this report represent but a small portion of the information available from the National Panel Study on Health and Aging. This analysis has focused on the use of formal and informal providers of a variety of types of long term care services and the levels of unmet need for these services. Particular concern has been directed to the involvement of informal providers in the provision of in-home health and personal care services which tend to require a level of skill which most family caregivers do not possess. Evidence has been demonstrated that many elders are receiving informal services for this skilled level of service, and many others are receiving no service at all. In areas where the home health service sector is well funded and many services are available, utilization patterns for formal providers are higher than in other sites. Interestingly, even when formal services are utilized, informal support continues to be offered at levels comparable to the sites where the service sector is not well supported. Although involvement in the formal sector does not substantially decrease the number of informal service users, it does decrease the number of unmet need(s) reported by the elders in this sample.

Families appear to be substantially more involved in the provision of chore services to dependent elders than in health and personal care. Levels of unmet need in this area are high also, and must not be ignored in the shift of attentions to more medicalized services. These chore services often enable the elder to remain independently in his/her own home.

Given that the use of informal service providers is quite substantial for both kinds of services and that involvement by family members may be more appropriate for one of the service categories than the other, it appears that two different strategies might be appropriate for policy makers to consider. First, the provision of quality, skilled in-home care must be made available to elders who need it and can benefit from it. This administration has implemented a cost containment policy which assumes the presence of a community-based service structure which often does not exist in many communities. Families are faced with elder members who are at least temporarily sicker and in need of the types of services such as IV therapy which few family members are capable of providing. If this policy of early discharge into the community is to continue, then we must urge the development and support of community services and skilled providers who can meet the needs of elders and avoid unnecessary institutionalizations. It seems that the development of a "humane," long term care system must address the issues of unmet needs and inappropriate demands on family for provision of care. Examination of findings from this study and from others in the U.S. as well as studies in other types of medical systems in other countries indicate that the fear of the "woodworking" effect is not well founded. Families continue to provide help to their relatives even when formal services are used. It should be our goal to develop a system which enables families to provide the kinds of services they are most capable of providing and which frees them from providing services they are not trained or capable of supplying. Thus, the second strategy must address the appropriate tax and service incentives to reward informal support when it is in the elder family member's best interest.

Some reorganization of the DRG system in terms of a "social" DRG is required to address the situation where an elder is discharged into the community while still needing substantial help but is denied access to a nursing home bed. In some cases, nursing homes refuse to admit patients whose needs require a very intense level of service. Families are certainly no better qualified to meet those needs. Changing reimbursement strategies to accomodate this transitional or subacute stage appears to be a necessary step.

Expanding the coverage of home health services under Medicare might help address the levels of unmet need for health and personal care services. Utilization of the formal services would increase, but they would increase as a result of meeting unmet needs--not as a result of families abandoning their responsibilities. As always, concern with cost containment must be a part of our decision making process about service delivery. Let us hope that equal concern can be directed toward the development of a humane, continuum of care system which adequately meets the needs of elders in this society.

FULL BIBLIOGRAPHIC CITATIONS, EXPANDED TEXT AND GRAPHICS PROVIDED UPON REQUEST TO FIRST AUTHOR.

Session G

Panel on Forecasting Health, Service Utilization, and Health Personnel Requirements

DATA FOR AN AGING POPULATION

HEALTH STATUS DYNAMICS AND HEALTH SERVICE UTILIZATION AMONG ELDERLY BLACKS AND WHITES: FINDINGS FROM NEW HAVEN EPESE PROJECT

Lisa Berkman, Ph.D. and Burton H. Singer, Ph.D.
Yale University School of Medicine

(Not available for publication)

LONG-TERM CARE: CURRENT ESTIMATES AND PROJECTIONS

Korbin Liu, Urban Institute and Ken Manton, Duke University

Demand for long-term care services is expected to increase based on projections of the growth of the population of older Americans. The 65+ age group is expected to increase from 25 million at the present time to 36 million by the year 2000. Perhaps more important, the growth of the 85+ age group is expected to increase at a faster rate reaching 5 million by the year 2000 from a current size of 2.5 million. While we can safely predict that the long-term care population will increase in the future, it is considerably more difficult to estimate the amount and types of services that will be required.

Long-term care refers to a wide range of medical, health-related and social services for persons who, because of chronic illness or disability, need personal assistance in caring for themselves over an extended period of time. Because long-term care services are usually required to compensate for functional disabilities such as dependencies in activities of daily living, the services tend to be low technology and labor intensive. Hence, many factors can contribute to the pattern of how and how much long-term care services are provided. In addition to health and functional status, these factors include the availability of family and friends to provide informal care at home, financial resources to pay for formal providers to complement or substitute for informal sources of care, and the availability and costs of various types of formal long-term care services.

The projection or forecasts of future long-term care requirements will depend on the relationships among need, informal care, financial resources, and costs of formal sources of care. These factors will in turn be affected by technological improvements and changes in public and private policies. In spite of the inherent difficulties of projecting such a complex phenomenon as long-term care, the importance of long-term care and its costs for individuals, their families and the general public is so great that such efforts are warranted. Projections of long-term care would serve a multiplicity of purposes, including the planning of health services, analyses of innovative options for financing long-term care, and assessments of cost-effective options for meeting the rapidly increasing demand suggested by demographic projections.

In this paper, we first examine characteristics of the long-term care population based on estimates from recent nationally representative surveys of older Americans. Second, we present a "base case" projection of future long-term care requirements based on the current estimates and population projections. Third, we present alternative projections of future long-term care based on assumptions about changes in the functional status of older Americans and nursing home bed supply. These alternative projections are intended to illustrate the effects of two of the many determinants of long-term care services. Finally, we discuss further areas of research that would enhance our ability to provide more accurate projections of long-term care.

Table 1 presents characteristics of the long-term care population residing in nursing homes and in the community. Recent surveys estimate a prevalence of 1.3 million nursing home patients and 5.1 million disabled older Americans residing in the community. Nursing home patients tend to be older, female, not married and more dependent in activities of daily living (ADLs). For example, while 50 percent of the nursing home residents are dependent in at least 5 ADLs, only 19 percent of community residents are that severely dependent in ADLs. However, by virtue of the larger base of community residents, the number of persons with severe ADL dependencies is greater among community residents. The overlap between the nursing home and community residents in terms of ADL dependencies is indicative of factors, other than functional status, that affect whether disabled individuals receive long-term care in nursing homes or in the community.

Table 2 presents the "base case" projections of the long-term care population. The estimates were derived by multiplying current estimates of the long-term care population, such as those in Table 1, by population estimates. This static component methodology assumes no changes in any of the current determinants of long-term care services. Table 2 shows that the total long-term care population will increase from 5.6 million in 1980 to almost 9 million by the year 2000. Major increases will occur in the size of the nursing home population, particularly between 2020 and 2040 as the "baby boom" cohorts reach the high risk long-term care ages. By the year 2040, the long-term care population will be triple the 1980 size and reach 18 million persons in nursing homes and in the community.

Table 3 presents projections of percentage changes of the long-term care population between 1980 and 2000 under alternative assumptions. These assumptions, all hypothetical, were derived to illustrate the effects on the size and locations of the long-term care population if changes occur in one or more of the factors determining long-term care requirements. The first column of Table 3 presents the percent change in the long-term care population of the base case projection, and is included principally as a reference for the alternative scenarios in the other columns of the Table.

The first scenario is based on a hypothetical decline in disability that is equivalent to projected declines in mortality. This assumption greatly reduces the growth of the long-term care population relative to the base case. Specifically, rather than a 57 percent increase under the base case, the effect of the hypothetical disability decline was to reduce the growth to 24 percent between 1980 and 2000. This is equivalent to a reduction of 2 million persons in 2000 from 9 million to 7 million.

The second scenario constrains the growth of nursing home beds to 50 percent of the current rate (i.e., to 1.1 percent per year), and illustrates effects of public policies, such as the tightening of Certificate of Need rules for nursing home bed construction. Unlike the first scenario, nursing home bed supply constraints do not affect the total size of the long-term care population, but redistribute the population by location of care. Specifically, some of the projected nursing home patients are backed out of nursing homes and placed in the community. The biggest effect is to increase the numbers of 85+ with high ADL dependencies in the community.

The third scenario is a combination of the first two where both disability decline and nursing home bed constraints are assumed. No change is seen in the size of the nursing home population between years 1980 and 2000, although the size of the total population in need is identical to the second scenario in which disability declined at the same rate as projected mortality declines.

The three hypothetical scenarios were derived to illustrate the effects of different factors on the size and the types of long-term care services that would be required in the future. While declines in disability, for example, would reduce total and component service requirements and costs, constraints on bed supply imply differential responsibilities by types of providers. Since most of the community based care is managed by individuals and their families, with relatively little support available from public programs, constraints on nursing home beds would place greater burdens on private resources, given current public program responsibilities. The hypothetical scenarios are also illustrations of simple assumptions involving only two factors in the most complicated case. It is apparent that projection or forecasting initiatives should attempt to address the multiplicity of factors that affect the size and types of long-term care that will be required in the future. Moreover, basic research on relationships among these factors would enhance our ability to improve our projections and forecasts.

The relationships among morbidity, disability and mortality should be a central area of further research. Aside from the fact that these conditions dictate the total size of the long-term care population, further research to better characterize each of them would assist in planning programs and policies. The types and severity of disability may change in character in the future, with potentially significant effects on types and amounts of long-term care services required. For example, increases in mild severity, associated with early stages of arthritis might result in greater need for community based care, while increases in Alzheimer's disease would probably increase the demand for nursing home care. Moreover, better knowledge about the relationships of disability and morbidity would provide insights on potential effects of preventative and curative technological innovations.

Changes in socio-economic characteristics of future cohorts of older Americans will also affect the demand and characteristics of long-term care services. For example, differences in the marriage rates from historical trends would affect the way in which long-term care services are obtained in the future. A lower than expected marriage rate would imply less informal care available and greater use of formal care providers. Similarly, declining fertility rates imply less availability of offspring as potential caregivers. Other conditions, such as increases in the labor force participation of women and corresponding increases in pensions available to women, would also affect the future demand for different types of long-term care services.

Public programs currently support very limited coverage for noninstitutional long-term care services and coverage for nursing home costs only for Medicaid eligible persons. These programs continue to be reviewed for possible changes to provide greater coverage for long-term care services. At the same time, private insurance policies, which cover no more than 2 percent of total national long-term care costs, are gradually being expanded to cover long-term care. The growing awareness that, unlike other forms of health care, long-term care costs are not generally covered by either Medicare or private health insurance suggests that increased knowledge may eventually be translated into policy changes in the future. Such policy changes would also affect the amounts and types of long-term care services that are provided.

Table 1

Characteristics of Nursing Home and Noninstitutionalized Disabled Elderly (65+) Populations

	1977 Nursing Home Residents (N = 1,126,000)	1985 Nursing Home Residents (N = 1,315,800)*	1982 Noninstitutionalized Elderly (N = 5,100,000)
Age			
65-74	18.7%	16.1%	43.5%
75-84	41.3	38.7	38.3
85+	40.0	45.2	17.8
Sex			
Male	26.1	25.4	35.9
Female	73.9	74.6	64.1
Marital Status			
Married	12.1	16.4	41.4
Not Married	87.9	83.6	58.6
ADL			
Bathing	88.5	91.2	47.4
Dressing	71.7	77.7	22.9
Toileting	54.8	63.3	22.9
Mobility	69.2	62.7[1]	44.2[2]
Incontinence	47.4	54.5	23.7
Eating	33.6	40.4	7.3
ADL Scores			
No ADL	7.4	7.6	31.1[3]
1-2	23.9	20.9	34.2
3-4	18.7	21.3	15.5
5-6	40.5	50.2	19.3
Other	9.5[4]	-	-

Source: Tabulations of the 1977 NNHS and the 1982 NLTCS.

* Esther Hing, "Use of Nursing Homes by the Elderly: Preliminary Data from the 1985 National Nursing Home Survey," Advance Data, No. 135, May 14, 1987.

1. Transfer in or out of a bed or chair.
2. Help getting around inside.
3. IADL only.
4. Combinations in Katz ADL Scale that were not transformable to ADL score.

Table 2

Number of Disabled Older Persons (in thousands) by Age, Disability Level, and Residence: 1980-2040

	1980	2000	2020	2040
COMMUNITY RESIDENCE				
Age 65-74				
IADL Only	679	787	1,291	1,253
ADL	1,211	1,414	2,320	2,266
Age 75-84				
IADL Only	545	878	1,044	1,710
ADL	1,175	1,889	2,240	3,672
Age 85+				
IADL Only	181	382	539	929
ADL	637	1,367	1,928	3,317
Age 65+	4,427	6,717	9,363	13,147
NURSING HOME RESIDENCE				
Age 65-74	225	263	443	436
Age 75-84	497	762	888	1,484
Age 85+	522	1,130	1,590	2,685
Age 65+	1,243	2,155	2,921	4,605
COMMUNITY AND NURSING HOMES	5,670	8,872	12,284	17,752

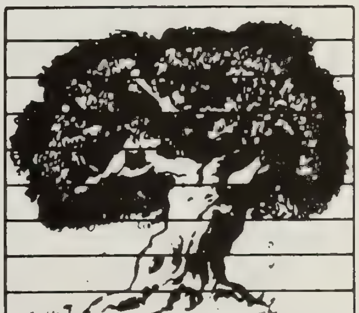
Table 3

Projection of the Disabled Elderly Population Under Different Assumptions: 1980-2000

	Base Case	Disability Decline	Supply Constrained	Disability and Supply
COMMUNITY				
Age 65-74				
IADL Only	16%	-3%	17%	-2%
1-2 ADL	16	-3	20	-1
3-4 ADL	17	-2	23	2
5-6 ADL	17	-2	28	5
Age 75-84				
IADL Only	61	29	65	31
1-2 ADL	59	27	68	33
3-4 ADL	62	28	81	40
5-6 ADL	64	32	94	50
Age 85+				
IADL Only	111	66	128	75
1-2 ADL	114	68	142	83
3-4 ADL	114	69	163	96
5-6 ADL	116	68	189	108
Age 65+	52	23	66	31
NURSING HOME				
Age 65-74	17	-2	-17	-24
Age 75-84	53	20	9	-7
Age 85+	117	51	54	17
Age 65+	73	29	23	0
TOTAL (CB+NH)	57%	24%	57%	24%

Session H

Characteristics of the Black Aged Population



DATA FOR AN AGING POPULATION

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DEMOGRAPHIC CHANGES IN GEORGIA'S BLACK BELT

Everett S. Lee , University of Georgia
Douglas C. Bachtel, University of Georgia

One of the most important demographic developments of this century is the redistribution of Black Americans. Before World War I about ninety percent of blacks lived in the South. Today, if we were to include Delaware, Maryland, and the District of Columbia in the Middle Atlantic States, where they more nearly belong rather than in the South, the black population would be more evenly split between the South and the rest of the nation. More important than the movement from the South to other regions, however, has been the movement out of rural areas into the cities. Until World War I it was almost true that the smaller the community the larger the proportion of blacks in the total population. Now the situation is reversed. Currently blacks are concentrated in metropolitan areas and within them in central cities. In the New York Metropolitan Area alone there are more blacks than in the entire state of Georgia. One of the greatest concentrations of minorities ever is that of blacks in Harlem. Similar enclaves, black cores in white suburbs, are found in most of our larger cities, making our Civil Rights dreams of integrated schools and integrated communities harder and harder to achieve.

Curiously, this shift of millions of people over long distances and between diverse areas has been accomplished with relatively low rates of black migration as measured over short periods. Rates of black migration for one or five-year periods have been low as compared with those of whites, but far greater redistribution was accomplished because there was so little return movement. Today, of course, we hear that blacks are returning to the South. The net from that movement, however, is very small, and few blacks joined in the much touted return to the countryside of the 1970s. Blacks, like the Irish of yesterday and immigrant groups of today, have spurned rural destinations. Thus, the central cities of the North and West have absorbed millions of black in-migrants , again that was offset by the contrary movement of Northern and Western whites into Southern suburbs.

Movements of these magnitudes leave residues. For the rural South the residues consist of underpriviledged blacks and whites still living in the so-called Black Belt. It is uncertain how the term arose, but it was in use well before the turn of the century to describe an essentially contiguous group of counties stretching from coastal Virginia through the plains and Piedmont sections of the Carolinas and Georgia into Alabama, Mississippi, and Louisiana. The general definition was that the Black Belt Counties had at least 50 percent black population, a classification accepted by U. B. Phillips and W. E. B. DuBois and adopted by most of the historians and social scientists who followed him.

This paper is an initial segment of a larger study of the demographic and economic development of the Black Belt and includes only Georgia counties. In that State, perhaps more than others, geography determined the location of the Black Belt. There it consists of two segments, the coastal counties and an arc of counties running northeast to southwest across the state. (See Figure 1) Oglethorpe, the founder of Georgia, had wanted neither blacks, lawyers, nor hard liquor in the colony, but the colonists found it impossible to get along without any one of the three. As rice and sea island cotton came to the fore, slaves were imported in large numbers and soon outnumbered whites. Later, with the invention of the cotton gin and the development of upland cotton, there was a mass movement of planters and slaves into the interior. Except in the coastal counties cotton was, from the beginning, the determining factor in the distribution of black population and it continued to be so until the drastic onslaught of the boll weevil in the 1920s.

Defined as including those counties that at any time before 1920 had at least 50 percent black population, the Black Belt includes 74 of Georgia's 159 counties. The large area in the southeast, which is not included in the Black Belt, includes the Pine Barrens and the wire grass lands. Settlers moved quickly through this area, still one of limited agricultural potential, to reach the better lands of the southwest and the initially fertile lands of the Piedmont. The block of counties to the north are the Upper Piedmont and Mountain Counties, marked off roughly by a fault that some geologists think is a seam left when lands from the African plate were welded to the North American plate as they collided and moved apart. Others see the dividing belt as the root zone for the Appalachians to the North. In either case the terrain to the North is rough and not suitable for plantations; consequently, it was largely developed by subsistence farmers and has since maintained a largely white population. In one of these counties there were not blacks in 1980; in others, like Forsyth County, only a few. Today, of course, there are many blacks in the non-Black Belt Counties of Fulton and Dekalb which together contain the central city of Atlanta. However, the predominantly black population of Atlanta is a post-World War II phenomenon.

Figure II for 1930 shows that along the coast, along the northern fringes of the Black Belt and along the Fall Line, counties had fallen below the 50 percent by which the Black Belt was defined. In part this was due to urbanization, in particular the growth of the State's six largest cities: Atlanta and Athens to the north, Augusta, Macon, and Columbus on the Fall Line, and Savannah on the Coast. Worth noting is that while the central cities eventually attracted large numbers of blacks, so many whites came to adjoining areas that much of the metropolitan areas became whiter than ever. In Atlanta, for example, the proportion of blacks in the Metropolitan Area as currently defined is about the same as fifty years ago, a balancing of central city black growth with suburban white growth.

Chart III shows a continuance of the process. Counties with 50 percent or more black population in 1980 were situated just above or just below the Fall Line and are contiguous to those which have 40 to 49 percent blacks. Again the spread of suburbanization and commuters is a factor, but so too are the military posts located near Savannah, Columbus, Macon and Augusta. Thanks to Georgia's climate and its habit of re-electing Congressmen, Georgia has been favored with military installations. Even the university city of Athens has one, the Supply School for the Navy, surely one of the most inland of naval establishments.

To this we might add that the interstate highways have had limited effect upon the Black Belt. I-85 runs along the northern limits of the Black Belt as does much of I-20; I-75 crosses it at a narrow dimension; I-16 scarcely touches it; and I-95 moves through an area which does not lend itself to industrial or agricultural development. An initial survey shows that except where interstate highways are within metropolitan areas or connect centers that are close to each other, they have had limited impact upon economic development.

In those areas of Georgia's Black Belt that have been influenced by metropolitan and military spread there has been considerable growth and development. In the other sections stagnation is the rule, a situation made nearly permanent by political fragmentation, racial discrimination, and a cavalier disregard for education. These are related items. Georgia has a plague of counties. There are 159 of them, and Georiga is second only to Texas in number and second to none in areal splintering. Education is county-controlled and schools are generally too small for efficient or economic education. In some counties of the Black Belt half or more of the white collar jobs are held by government workers, a factor which combines with racial considerations to bring about a fierce resistance to county consolidation or state interference with local schools. When the state recently allocated funds for the improvement of local schools some counties chose to use them to reduce taxes. Georgia continues to rank near the bottom in standardized test scores and in years of school completed, and near the top in the number of high school dropouts.

Remaining in the non-metropolitan part of the Black Belt was and is, for most persons, an acceptance of low income, low status, and little opportunity for children to prepare themselves for the future. For some whites there was the offsetting factor of the ownership of land; for blacks who were small owners or croppers this factor hardly applied. For both, unawareness of the outside world or lack of preparation for life elsewhere were major reasons for remaining. As education and communication improved, more and more youths could make a choice, and in migrating they left behind older persons, the least educated, and children already engendered. Age, educational, and marital structures were distorted, so much so that some counties now struggle for demographic as well as economic survival.

In the Georgia Black Belt heavy losses of population were common despite continuing high birth rates. For the 74 counties maximum popluations at any census from 1790 to the present have been ascertained and compared with the 1980 populations. From their peaks forty-five had suffered losses of total population, one by more than 75 percent and 13 by 50 percent or more. Losses of white population were less severe. Still 40 counties were below their maximum white populations, usually reached between 1890 and 1910, and 12 were 50 percent below their highest totals. Among blacks the losses were even greater, running up to 80 percent. Sixty-one counties had lost black population, half of these by 50 percent or more.

Most of the gaining counties had been incorporated into the growing cities. Eighteen of the 29 counties gaining in total population, 14 of the 34 gaining in white population, and 10 of the 13 gaining in black population were metropolitan in 1980. Only two rural counties gained in total and white population and none in black population.

The heavier losses in black population resulted in a general "whitening" of the Black Belt. In only one county, Hancock, was there an increase in the proportion of black population, and in others there were huge decreases from peak proportions. This was particularly true in the six coastal counties. For example, Glynn went from 87 to 26 percent black, Camden from 77 to 32 percent, Chatham from 77 to 38 percent, Bryan from 81 to 22, and Liberty from 78 to 37.

The general decline in population did not result from a disproportionate decline in birth rates. On the contrary, high birth rates prevailed for both blacks and whites until recently, and the fall for whites is related to the aging of population, as well as, to contraception or abortion. For blacks especially, but for whites also, births to teenagers and to women without husbands have prevented a greater decline in the birth rate.

The loss in population or the failure to increase in population at the national or state rate is attributable to out-migration. Not only has the out-migrabeen heavy, it has been highly selective for young people. This is best shown through estimates for the 1950-60 and 1960-70 decades in a cooperative effort of the University of Georgia and the Department of Agriculture. Almost all of the Black Belt Counties that had not become metropolitan suffered severe losses through migration, as high as 25 percent of expected survivors in a single decade.

For purposes of illustration, four counties have been selected to show the effects of such out-migration on the race and age structure of population. In the lower Piedmont these are Hancock County, down 50 percent from the peak in total population and nearly 80 percent in white population; and Taliaferro County, off by nearly 80 percent in total and black population. At the other side of the state are Webster and Quitman, both in an area where "Princess of Emigrants" were once wringing fortunes from slaves and cotton. Webster has fallen by two-thirds in total population and Quitman by a half. In both, heavier losses were experienced by the black population.

The rates of net out-migration for these counties are very high. For Hancock and Quitman the net migration losses of total population for 1960-70 were over 20 percent, and for Webster and Quitman 33 percent. At the ages of maximum migration, either 20-24 or 25-29, they were 54 to 68 percent. Obviously, drains of this magnitude quickly change the population mix. However, as shown by the population pyramids presented for 1980, the results are quite different for blacks and whites.

The most extreme of these counties is Taliaferro where a loss of nearly 80 percent from the peak population has reduced it to 2000 people. Of these, whites number 711 and their median age is 43. That figure, however, does not indicate the drastic condition of the white population. In this county there are more whites 75 and over than there are 15 and under, and more whites 65 and over than there are 25 and under. The black population presents a different, but also troublesome picture. Here there are relatively large numbers of children, few people in the usual parental ages, and a swelling number of oldsters at the top.

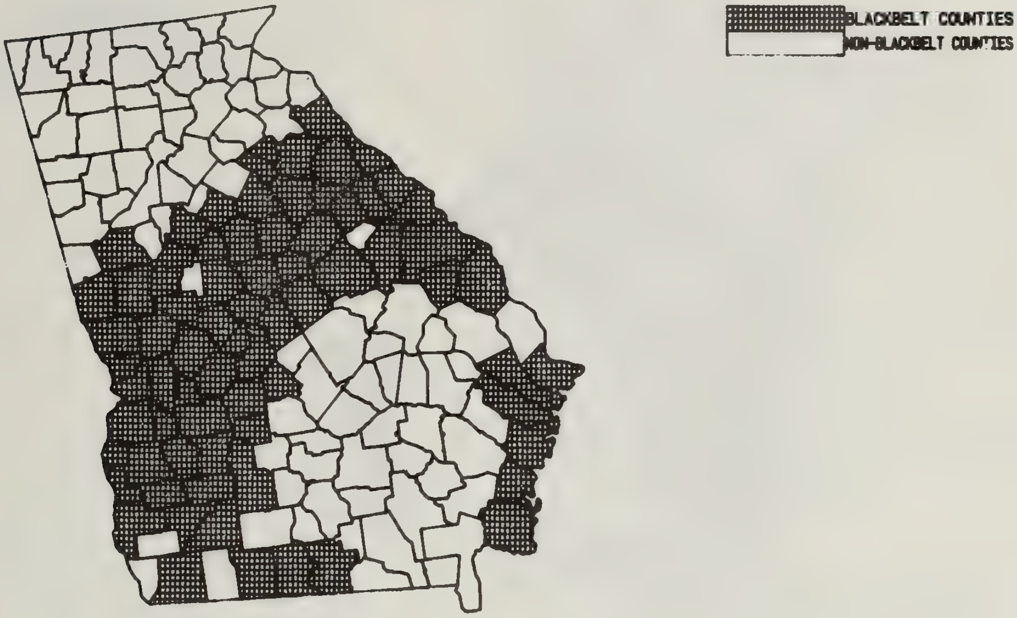
In less extreme fashion, the other three counties yield the same picture of aging white populations with relatively few children, proceeding it would appear in the same manner that has brought Taliaferro to its present demographic position. Also, there is a similar, but not so extreme, a pattern for blacks. Again, there are relatively many children, a shortage of young and middle-aged adults, and a goodly number of old people. The shortage of males in the working ages is particularly marked.

Of course, such population structures have social and economic determinants and consequences. Black Belt counties are poor counties and blacks have been able to acquire little education. For the four counties discussed above the median number of years of education completed in 1980 was 7 or 8. for the total populations of these counties the percent below the poverty level ranged from 30 to 40 percent. For blacks it was much higher, seventy percent or more in each of the four counties and 92 percent in Taliaferro County. Making a bad situation worse was that half of the births in these counties were illegitimate and a third were illegitimate births to teenagers.

These are not average counties in the Black Belt, but many others are like them. For the counties that have not been incorporated into the expanding metropolitan areas education is limited and income low. With little opportunity for employment in the home county, workers are forced to commute and high proportions depend upon old age assistance, aid to dependent children, food stamps and other transfer payments. What has happened in the Black Belt has been an adjustment to resources through heavy out-migration, leaving behind an aging population burdened with an excessive number of children. Often the fathers of the children are not around, and in many cases the children live with grandparents who support them with Social Security and other transfer payments. It would appear that further adjustments to local resources must be achieved through net out-migration, but the children are being poorly prepared for this eventuality. In extreme cases, counties can be thought of as dying as the young move away and the old pass away.

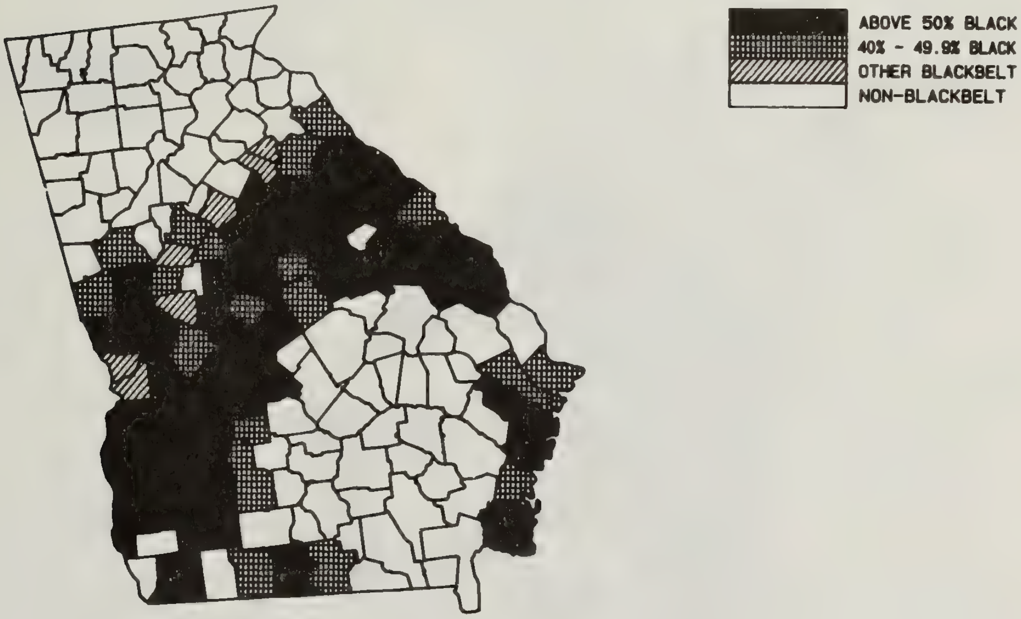
GEORGIA BLACKBELT COUNTIES

FIGURE 1



GEORGIA BLACKBELT COUNTIES: 1930

FIGURE 2



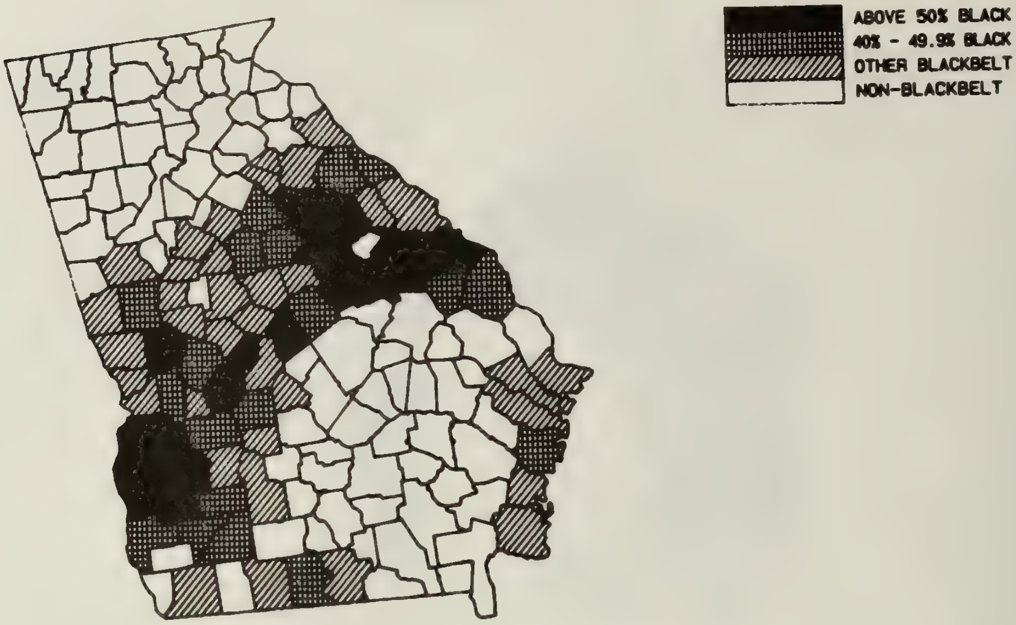

GEORGIA BLACKBELT COUNTIES: 1980

FIGURE 3

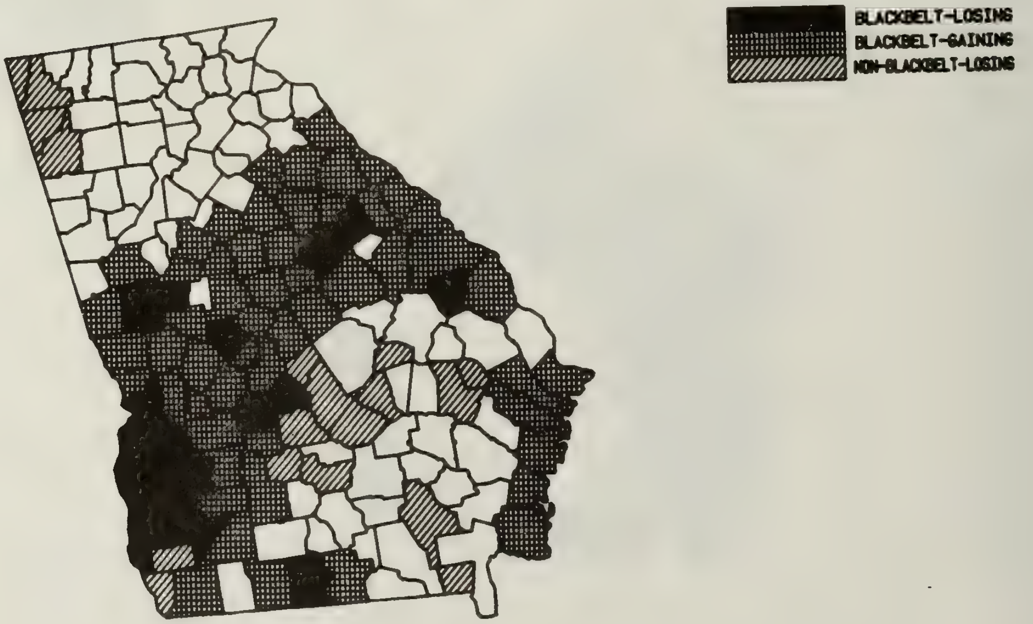

POPULATION LOSS: 1980 - 1986

FIGURE 4

THE STATISTICALLY INVISIBLE MINORITY AGED

Cynthia M. Taeuber, Bureau of the Census
and
Ernest B. Attah, Atlanta University

The elderly" is a phrase commonly used to describe the 29 million people aged 65 and over. There has long been a tendency to use statistical averages for the total population 65 and over as if they were a homogeneous group. In recent years, however, data producers have begun to disaggregate the data to show more age detail and, not surprisingly, there are significant differences in a group that covers a 40-year age span. Circumstances can be very different for a 65-year-old married couple than they are for an 85-year old-widow.

Even when age and gender differences are shown in tabulations, data from surveys tend to be analyzed for the total population, and not for the race or ethnicity groups within the older population. Because the White population is such a large part of the older population (90 percent in 1980), averages for the "total population" are really descriptions of the White population and thus, do not provide a complete view of the diversity within the older population for those who make policy. For example, the 1980 census reported that 15 percent of "the elderly" were poor; the poverty rate for White elderly was 13 percent but 35 percent for the Black elderly. And, from more detailed tabulations, we found that poverty rates varied from 7 percent for White males aged 65 to 74 who lived in families to 73 percent for Black females 85 and over who lived alone.[1]

The remainder of this paper will use the Survey of Income and Program Participation (SIPP) to show some illustrative differentials within the older population for the various age, sex, and race groups. We argue here that overall averages used to describe the older population are misleading and that data producers should show age, sex, and race differentials in the data to the extent possible. Because of sample sizes in surveys, such detail has not usually been feasible and so we suggest several statistical approaches to the problem. The data are subject to various nonsampling errors, such as undercoverage of the population, processing errors, and respondent reporting. Certain measures, such as quality control programs, are implemented to reduce these errors. In addition, if this survey were repeated with different samples of respondents, the results would vary from sample to sample. Standard errors indicate the magnitude of this sampling error and partially measure the effect of some nonsampling errors. Confidence intervals are constructed from the sample estimate and its standard error. If an estimate and its standard error were calculated from all possible samples, about 90 percent of the intervals from 1.6 standard errors below the estimate to 1.6 standard errors above the estimate would include the average result of all possible samples. For a particular sample, one can say with a specified confidence that the average derived from all possible samples is included in the confidence interval.

DATA SOURCES

Decennial censuses have traditionally been thought of as the only reasonable source of detailed tabulations for the study of relatively small population groups. For instance, the 1980 decennial census provided data by age, sex, and other characteristics for the race/Hispanic origin groups. The 1990 census will provide more age detail cross-classified by sex and other demographic, social, and economic characteristics for the race[2] and Hispanic-origin groups. The census has many advantages over any other data source as it provides reasonably reliable, detailed tabulations below the national level. But the census is taken only once every 10 years and the questions are general purpose. Censuses focus on demographic, social, and general economic characteristics of the overall population. In the past, health questions relevant to the older population have not been asked. In 1990, it is planned to ask questions about whether a person has difficulty with activities of daily living inside the house and outside the house. There is no space on a decennial census to ask a series of detailed questions on a particular topic. That is the job of national surveys.

National recurring surveys such as, for example, the Current Population Survey (CPS), the Health Interview Survey, and the Survey of Income and Program Participation (SIPP), ask detailed questions on various topics of interest in the study of the older population. But they provide data only at the national level for the

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most part. Further, for the study of the characteristics of the older population by age, sex, and race/Hispanic origin, sample sizes present a significant barrier because it is difficult to obtain statistically reliable point estimates for small groups. In this paper we will demonstrate two approaches for meeting the sample size problem.

Answering policy questions about "the elderly" and their role in American society has also been hampered by the specialized nature of existing data sets. Generally, the data sets are not designed to simultaneously measure a variety of social, economic, and health characteristics and changes in these characteristics over time. The Survey of Income and Program Participation (SIPP) is a source of very detailed data on the social, economic, and health characteristics of the population, including information on eligibility and participation in government transfer programs, and thus, is potentially a rich source for research on the older population.

SIPP, first administered in October 1983, is a nationally-representative household survey that provides detailed, longitudinal information on income, living arrangements, disability, assets and liabilities, government transfer program eligibility and participation, pension coverage, taxes, and many other characteristics of individuals. The survey was designed to increase the accuracy of economic data collected by asking detailed questions (e.g., 56 income sources) frequently and to provide data on changes in characteristics over about 2 1/2 years. Respondents are interviewed 8-9 times, or once every 4 months when they update information on their characteristics. New panels (samples) are introduced each year. There were about 19,200 interviewed households in Wave 3 and 18,900 in Wave 4 of the 1984 panel, the samples for which data are shown in this paper. The longitudinal design of the survey allows for the study of changes in characteristics such as marital status or living arrangements and the relationship of such changes to other characteristics, for example, income or program participation. Survey data can be used to assess future program coverage and costs and to determine the effects of proposed changes in program eligibility rules and benefit levels.[3]

In addition to files containing SIPP core questions that are asked at each interview, and longitudinal files of the core data, files are also available from topical modules (questions centering on particular subjects) which are administered periodically during the survey. In Wave 3 of the 1984 panel, a topical module on "Health and Disability" was conducted and in Wave 4, a module on "Asset Holdings" was conducted. With funding from the National Institute on Aging, the two topical modules were merged into one file, the "SIPP Health-Wealth" file.[4] This file contains data on the ability of persons to perform a set of sensory and physical activities, disabilities that limit or prevent work, the need for personal assistance, health insurance coverage status, and the income, wealth and assets of persons.

While the "Health-Wealth" file presents a unique opportunity to develop detailed cross-tabulations of the health and economic status of persons, the sample size for the older population is a limitation. There were over 11,000 sample cases of persons aged 55 years and over but of that group, 3,500 were aged 65 to 74 and only about 1,900 cases were persons aged 75 to 84 and 400 were 85 and over. Of the 2,300 cases who were 75 or older, nearly 2,100 were White and nearly 200 were Black; 1 was an American Indian, and about 20 were Asian or Pacific Islanders. Less than 60 cases were persons of Hispanic origin.

PROBLEM OF WHAT AVERAGES REFLECT

Averages can be like the man with his head in the freezer and his feet in the oven who, on average, feels fine. As discussed above, researchers came to realize that "the elderly" as a statistical average was misleading to those making policy. We argue here that age detail alone can still provide a misleading picture, and that gender and race differences are important variables to consider for evaluating programs and developing policies.

The White population comprises about 90 percent of the elderly population, and thus, averages for the "total" population reflect primarily the characteristics of the White population. SIPP is the example used here but the problem holds for any census or survey.

STATISTICAL APPROACHES TO SMALL SAMPLE SIZES

In the 1980 census, of the 25.5 million persons aged 65 and over, 23 million were White (90 percent), 2.1 million were Black (8 percent), and the remainder were other races of whom about 200,000 were Asian or Pacific Islanders and 75,000 were American Indian, Eskimo, or Aleut. There were also about 700,000 persons of Hispanic origin (could be of any race).

As mentioned above, the decennial census is the most important source for studying the details of age, sex, and race differentials within the older population. In fact, for the elderly Asian and Pacific Islander, and American Indian and Alaska Native populations, the census is the only practical source for such detailed study and we have no realistic suggestions for the use of the sample surveys that currently exist to study the elderly among these populations.

The most commonly suggested solution to the problem of studying small-sized population groups is to increase the sample size of the particular population in question. The elderly population is technically an easy group for federal data developers to oversample because Medicare records can be used as a sampling frame. But in Medicare files, race is specified only for the White and Black population. For the Hispanic-origin population, coding of Hispanic surnames is a possibility. Undercoverage of Black males is, however, a problem in Medicare files just as it is in surveys.[5] For future surveys, we urge consideration of oversampling the total population 75 and over but particularly the Black and Hispanic-origin population aged 75 years and over. For other minority elderly, there is no easy solution and the cost is probably prohibitive unless their size increases substantially.

Even if sample sizes are increased in future surveys, a great deal of existing survey data remains underutilized for the study of White-Black differentials within the older population, and for more recent surveys, Hispanic-origin differentials. Large sampling errors have always seemed to be a roadblock. One solution is for data producers to combine data from several years of survey data to increase the sample size used to produce averages (this would probably be the most useful approach for the study of Hispanic-origin differentials). A second solution is to show data in confidence intervals rather than as point estimates, thus providing a clearer sense of the variability among groups even if confidence intervals are large for a particular small population group.[6] Showing confidence intervals does not overcome the problem of small sample size but does bring it to our attention in a straightforward way. Multi-variate techniques could also be used, but they are beyond the scope of this paper.

The first option to use currently available survey data by combining data from several years of a survey, has been considered for use with the annual demographic March Supplement Current Population Survey, for example. We could average 3 to 5 years of data together to produce more reliable data for smaller groups within the total older population. Funds currently are not available to try this approach but it seems to be a technically feasible and reasonably cost-effective approach to building historical data files for 3 to 5 years of age, sex, and White, Black, and Hispanic-origin differentials for the older population. The approach could work with other recurring surveys.

The second option, the use of confidence intervals to show relative differences among groups, is shown below with data from SIPP.

CONFIDENCE INTERVALS WITH SIPP HEALTH-WEALTH FILE

The following data are examples of the fallacy of talking about "the elderly" as if they were a homogeneous group. They show significant differences in health and economic characteristics among the age, sex, race groups. In general, older Black women have higher rates of health problems and lower incomes than do White men and women and Black men. Where the number in a population group is small, the data are shown in 90-percent confidence intervals rather than as point estimates. Estimates are statistically different if their confidence intervals do not overlap. A population subgroup ("base") had to be at least 200,000 for data to be shown because the number of cases in the sample would have been less than 50. Because of this requirement, data could not be shown for some detailed tabulations, especially for Black males. Also, throughout for SIPP data, where the term "White" is used, the data are actually for "all races other than Black."

Functional Limitations

Difficulty in performing personal care and home management tasks, that is, functional limitations, are indicators of the quality of an individual's life and the need for health and social services. Regardless of race or sex, functional limitations increase with age, but at a different rate among groups. Questions were asked in SIPP, about the ability to perform a set of sensory and physical activities including seeing, hearing, speaking, lifting or carrying, walking, using stairs, getting around inside the house, getting around outside the house, and getting into and out of bed. Except for speaking, persons with a difficulty performing an activity were asked if they could do it at all.

In general, persons aged 65 and older were more likely than younger persons to have one or more of these functional limitations and the limitations were more likely to be severe, that is, they were unable to do the activity at all.

The rate of limitation was higher among elderly Blacks, especially Black women, than among Whites. Among the population 65 years and over, 8 out of 10 Black women had one or more limitations compared with 7 out of 10 Black men, 6 out of 10 White women, and 5 out of 10 White men. The limitations were more likely to be severe among elderly Black women as about half had limitations that were severe compared with about 30 percent of Black men and White women and one-fifth of White men.[7]

For the total population aged 65-74, there was an inverse relationship between the level of household income and functional limitation status as shown in Table 1. Among Black women aged 65 to 74, from 65 to 80 percent of those with a limitation had monthly household incomes below $900 compared with 33 to 62 percent of those with no limitations. For those with monthly incomes of $2,000 or more the difference was not statistically significant as 0 to 8 percent had functional limitations and 4 to 24 percent had no limitations. Table 1 also is illustrative of the differences between Whites and Blacks within the same age and income categories. Only 22 to 29 percent of White men and 39 to 45 percent of White women with one or more limitations had monthly incomes below $900 compared with the 65 to 80 percent for Black women and 36 to 60 percent for Black men (difference is not statistically different from White women).

Work Disabilities

As retirement age is raised to keep the Social Security system and pension plans solvent, we should know that a significant minority of all persons aged 65 to 72 have disabilities that prevent them from working (Table 2) and the proportion of Blacks with a work disability is higher than for Whites (interestingly, there are no gender differences within a race group). Among Blacks aged 65 to 72, roughly half to two-thirds had a work disability; additionally, 35 to 55

TABLE 1. Functional Limitations Status of Noninstitutionalized Persons Aged 65 to 74, by Monthly Household Income, Age, Sex, and Race: 1984 (Waves 3 and 4 of SIPP)
(Numbers in thousands. Percents in 90-percent confidence intervals.)

Functional Limitations Status	Total, with income	Less than $900	$900 to $1,999	$2,000 or more
Total	16,306	28.0 - 31.2	41.4 - 45.0	25.6 - 28.8
Black Males	554	32.7 - 50.9	34.9 - 53.3	7.7 - 20.5
White Males	6,519	16.0 - 20.4	45.2 - 50.8	30.6 - 35.8
Black Females	828	58.2 - 72.6	20.9 - 34.5	3.1 - 10.7
White Females	8,405	31.4 - 36.0	38.4 - 43.2	23.3 - 27.7
No Limitations	8,176	18.8 - 22.8	43.0 - 48.0	31.2 - 36.0
Black Males	207	17.5 - 45.5	35.1 - 65.3	6.6 - 30.0
White Males	3,564	10.4 - 15.6	44.3 - 51.9	35.2 - 42.6
Black Females	233	33.1 - 61.5	24.7 - 52.3	4.3 - 24.3
White Females	4,172	22.4 - 28.6	40.0 - 47.0	27.7 - 34.1
One or More Limit.	8,130	36.0 - 40.8	38.3 - 43.3	18.8 - 22.8
Black Males	347	36.4 - 59.6	29.0 - 51.8	4.2 - 19.2
White Males	2,955	21.9 - 29.1	43.9 - 52.3	22.6 - 30.0
Black Females	595	64.6 - 80.4	16.0 - 31.0	0.5 - 7.5
White Females	4,233	38.5 - 45.3	34.8 - 41.6	17.2 - 22.8

TABLE 2. Work Disability Status of Persons Aged 65 to 72, by Sex and Race: 1984 (SIPP, Wave 3)
(Numbers in thousands. Percents in 90-percent confidence intervals.)

Sex, Race	Total	Percent with a work disability	Percent prevented from working
Black Males	448	47.7 - 67.9	34.7 - 55.1
White Males	5,415	36.7 - 42.5	24.8 - 30.0
Black Females	653	49.2 - 66.8	43.2 - 61.0
White Females	6,707	33.1 - 38.5	25.3 - 30.3

percent of Black men and 43 to 61 percent of Black women were prevented from working (the difference between Black men and Black women is not statistically significant). From 25 to 30 percent of White men and White women were prevented from working.[8]

Retirement and Functional Limitations

"Retirement" is a continuum of those who receive retirement income (Social Security, public and private pensions) and who were never in the labor force, those who have left the labor force entirely, and those who remain in the labor force, part time (less than 35 hours per week) or full time, part year (less than 50 weeks) or full year.

Of those persons aged 65 and over who received retirement income and worked, most worked all 18 weeks of the survey-question period (full year data are not yet available). The difference between working 1-17 weeks and working 18 weeks was statistically significant regardless of race or gender except for Black males with no limitations and Black females with one or more limitations.

Not enough Black men aged 55 to 64 and Black women aged 55 to 59 received retirement income to include in the study (less than 175,000). There were, however, over 3 million White males and 3 million White women aged 55 to 64 who received retirement income.

Among those aged 65 to 69 who received retirement income, there was no statistical difference between the proportion of Whites and Blacks who worked and had a functional limitation (4-6 percent for Whites, 1-8 percent for Blacks). For both groups, the percent working with functional limitations was relatively low (Table 3). Of persons with retirement income in the 65-to-69 year age group, 52 to 69 percent of Blacks did not work and had one or more functional limitations compared with 37 to 43 percent of Whites. Less than 2 percent of Whites worked if they had pension income and a severe limitation; there were no sample cases of Blacks who received pension income and had a severe limitation.

Some research has indicated that older Black women are more likely to work than are others when they have functional limitations because of their limited economic resources[9]. SIPP would be ideal for studying this question if the sample size were larger. There were only 253,000 Black males and 350,000 Black females aged

TABLE 3. Functional Limitations Status of Persons Aged 65 to 69 with Retirement Income, by Employment Status and Race: 1984 (SIPP Waves 3 and 4)
(Percent in 90-percent confidence intervals. Percent of age/race group based on 603,000 Blacks and 7,404,000 Whites.)

Functional Limitations Status	Did not work	Worked
BLACK		
No limitations	19.1 - 34.7	3.6 - 13.4
One or more limitations	51.8 - 69.0	0.7 - 7.7
One or more severe limitations	24.0 - 40.6	-
WHITE		
No limitations	41.5 - 46.7	7.0 - 10.0
One or more limitations	37.4 - 42.6	3.7 - 5.9
One or more severe limitations	15.3 - 19.3	0.6 - 1.6

· Indicates zero sample cases.

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65 to 69 who received retirement income. In this case, the difference by race and gender among those aged 65 to 69 who received retirement income and who worked with one or more functional limitations was not statistically significant (for Black males, 1-16 percent; Black females, 0-5 percent; White males, 4-7 percent; and White females, 3-6 percent). Future work with the SIPP Health-Wealth file will look at the work status and functional limitations status of the older population who do not have retirement income. Information about health as it is related to assets will also receive attention.

CONCLUSIONS

From the illustrative decennial census and SIPP data shown above, it is obvious that there are significant differences within the older population and within detailed age groups among the race groups. To the extent that policy makers must rely on statistical averages, policy cannot reflect the differences among the elderly groups. The near statistical invisibility of the minority aged may make it difficult for these groups to bring their concerns to the attention of policymakers. In some cases, more detailed information can be shown by statistical techniques so that at least relative levels can be determined. But at times, even these techniques are not sufficient and increased sample sizes for the minority aged in upcoming surveys are needed to address certain policy questions.

The preliminary data from the SIPP Health-Wealth file shown here are indicative of the information that can be gained when the interaction between health and economic factors are considered. We urge consideration of additional ways to use the SIPP longitudinal files in the study of the older population. We also urge that other surveys on the older population collect both health and socio-economic characteristics.

1. U.S. Bureau of the Census, 1980 Census of Population, Special Tabulations prepared for the National Institute on Aging. These "Special NIA Tabulations" by detailed age, sex, and race/Hispanic origin, are available from the National Archive of Computerized Data on Aging, Survey Research Center, University of Michigan (telephone: 313/764-2570). Also available is a data file of selected tabulations from the 1980 census Summary Tape File 5, also by detailed age, sex, and race/Hispanic origin.

2. White; Black; American Indian, Eskimo, or Aleut; Asian or Pacific Islander; Other races.

3. U.S. Bureau of the Census, "Using the Survey of Income and Program Participation for Research on the Older Population," David B. McMillen, Cynthia M. Taeuber, and Jennifer Marks, SIPP Working Paper Series No. 8503, September 1985, pp. 1-2. Additional information on SIPP is in Series P-70 reports and in "An Overview of the Survey of Income and Program Participation: Update 1," by Dawn Nelson, David B. McMillen, and Daniel Kasprzyk, SIPP Working Paper Series No. 8401, December 1985.

4. A machine-readable file is publicly available from the Inter-University Consortium for Political and Social Research, Box 1248, Ann Arbor, MI 48106 (Phone: 313/764-2570).

5. U.S, Bureau of the Census, "Methodology for Developing Estimates of Coverage in the 1980 Census Based on Demographic Analysis: Population Aged 65 and Over in 1980," by J. Gregory Robinson, *Preliminary Evaluation Results Memoranda*, No. 116, 1987.

6. This approach was also used in a study of the centenarian population from the decennial census. See "America's Centenarians: Data From the 1980 Census," by Gregory Spencer, Arnold A. Goldstein, and Cynthia M. Taeuber (U.S. Bureau of the Census), Current Population Reports, Series P-23, No. 158, U.S. Government Printing Office.

7. U.S. Bureau of the Census, Current Population Reports, Series P-70, No. 8, "Disability, functional Limitation, and Health Insurance Coverage: 1984/85, Table B, U.S. Government Printing Office, Washington, D.C., 1986.

8. *Ibid*., Table D provides point estimates.

9. Linda L. Belgrave and Marie R. Haug, "Interaction of Health and Pension: The Effects of Women's Early Retirement," paper presented at 1987 Public Health Conference on Records and Statistics, Washington, D.C. Research supported by the National Institute on Aging.

Education and Black Survival in the South

Anne S. Lee

Today's elderly owe their educations to the school systems of a simpler age, before this country had been changed forever by international conflicts, the Civil Rights movement, and the computer age. Such systems may have worked well in some areas but for the majority of elderly blacks, and especially those in the South, these often meant a life little touched by formal education. On the eve of World War II, more than half of all blacks reaching age 25 in this country had completed as little as eight years or less of schooling, and for most it was less. Only one in five had finished high school. Yet this was the best educated age group in the United States among those over 25, for with every succeeding age group, the level of education dropped sharply. (1)

Twenty years later, just before Brown vs. the Board of Education and the Civil Rights movement were to change forever American education, the national situation was better. Only a third of blacks aged 25-29 had ended their educations in eight years or less, but fewer than two out of five had completed high school. Again, education declined with each successive five-year age group and by age 45 the proportion of high school graduates was half what it was at 25.

The South

Educational levels in the South were always worse than in the rest of the country. In 1940, better than three-fourths of Southern blacks aged 25-29 had ended their education at the eighth grade or before and the proportion completing high school was about one in 16 for black males and one in ten for black females. The proportions with eight years or less of schooling rose sharply with age and from age 40 onward about nine out of ten Southern blacks had had only an elementary school education.

The South continued to lag well behind the Nation even though conditions had improved by 1960. Still, half the black males and two-fifths of the black females aged 25-29 had completed eight years or less of schooling while but a quarter of the males and a third of the females could boast of a high school diploma. Again, as in 1940, education levels dropped sharply for every successive age group and by age 40 the proportion of black high school graduates in the South was half what it was for those 25-29.

Changes in Educational Levels by 1980

These are the distributions, then, which obtained when today's elderly blacks reached the age when formal education is normally completed. Those who had reached 25 by 1940 were 65 or more in 1980 and even those who were 25 in 1960 were 45 by 1980. Though some persons, especially those who pursue postgraduate education, do complete further education in their late twenties and beyond, this is not usual and for those with the lowest educational attainment, formal education would have ended long before the age of 25. One would expect, therefore, that barring some selective process in mortality or massive migration of blacks into or out of the country, national educational distributions for older blacks would change little over time.

If we follow the educational distribution of black cohorts by decade, using national census data for 1960-1980, we find that educational levels tended to increase. The proportions who were high school graduates rose while those with eight years of schooling or less declined for males and females alike in every five-year group from age 45 to 74 as of 1980. Increases were largest for the youngest group and became smaller with age. Though not as large, similar increases were found when only those completing at least a year of college were considered but there was little difference by decade in the proportion of college graduates in any age cohort. This latter finding is a little surprising because these are the levels where additional education might be expected to have taken place.

These changes in educational distributions support an explanation of selective mortality at work. Kitagawa and Hauser reported as early as 1973 that mortality varies inversely with education so the improvement in educational distributions among middle aged and elderly black cohorts could well be a function of differences in survival. Knowing what we do about the economic and health status of poorly educated blacks in this country, selective mortality must clearly have been operating. But the facts for the upper educational levels belie this as the complete explanation. Beginning with those whose education ended with high school and for almost all the age groups with any level of college, the number of persons in a cohort actually increased over at least one decade. Many of these increases took place over the 1970-1980 decade but there were cases where an age-education cohort was actually larger in 1980 than in either 1960 or 1970. That any increase should occur is startling because, based on changes in the total cohorts, these age groups would be expected to decline by at least five percent each decade and among black males over 60 by at least ten percent. Furthermore, data for 1960 are for nonwhites and therefore include nonblacks, which would distort numerical comparisons.

Some of these increases, especially among those with post-collegiate education, represent real increases in educational attainment. It seems unlikely, however, that they all are because of the advanced age of those who would have been attending school.

Immigration, too, may have had some effect. The 1970's witnessed black movement into the country, from Latin America in particular, and reported education levels for some of these immigrants was high. It is true that the number of blacks reported as foreign born rose sharply between 1970 and 1980 but the preponderance of the new foreign born were young. In no cohort beyond 45 were the foreign born as much as five percent of the total. Moreover, half the black foreign born reported that they had arrived before 1970 and black migrants from abroad during 1975-1980 comprised less than one percent of the black population over 45.

Another possibility is that the quality of enumeration improved. This was clearly operating between 1970 and 1980 in the younger age groups which are below the scope of the present report. But if better coverage explains the growth of older cohorts, then enumerations were improving among those not normally included in the hard-to-find, namely, well-educated middle-aged and elderly persons.

The Situation in the South

Like the country as a whole, educational levels in the South also improved over time for individual black cohorts, according to census data for 1940-1980. True, educational attainment was still low among older blacks in 1980 but the proportions with the least education had declined while those in the upper educational categories had increased. For example, for black males aged 65-69 and 70-74 in 1980, the oldest cohorts which can be followed, the proportion of high school graduates doubled between 1940 and 1980 and similar increases were found for those with any college and for college graduates. Though less striking than for males in terms of the magnitude of the increase, the same pattern emerged for black females in these age groups. Furthermore, if the five-year age groups for blacks aged 45-64 in 1980 are followed over the twenty-year period 1960-1980, similar patterns of rising proportions of high school graduates and persons with at least a year of college emerged. These increases ranged upward as high as 12 percentage points for males and six for females. The proportions of college graduates, however, stayed just about the same.

Even more noteworthy was the fact that older cohorts with the most education actually increased in size. Examples of this could be found in each decade but the most striking occurred for 1970-1980. In that decade, the number of college graduates as well as persons with at least a year of college increased in every female cohort aged 45-74 in 1980 and for males in the cohorts aged 45-69. The number of high school graduates also increased, for males in the cohorts aged 45-64 in 1980 and females 45-69. Nor were these increases small, ranging as they did as high as 30 percent for the college-educated and 20 percent for the high school graduates.

As noted earlier, these changes parallel those which were observed for blacks in the United States as a whole and the same processes already discussed must also have been at work. But the evolution of the educational structure of elderly blacks in the South today is more complex because older Southern blacks are the survivors of major demographic changes which have taken place in that region over the last fifty years, the most important of which was the massive migrations which redistributed black populations out of rural areas and out of the South altogether.

Because of their magnitude, the movements of blacks out of the South were bound to affect educational levels. Two sources of lifetime migration data have been selected to examine this. The 1967 Survey of Economic Opportunity (SEO) makes it possible to consider separately the urban and rural origins of black Southerners (2) while census data can be used to examine older migrants in terms of region of birth.

While it is well known that migration tends to be selective of the better educated (Thomas, 1938; Lee, 1952: Lee, 1965), there was little to select from among older Southern blacks, so concentrated were they at the lower end of the educational scale. What outmigration from the region did accomplish was to reduce sharply the number of blacks in the lowest educational categories because, up until the 1967 SEO, there had been little in-migration to the region to offset losses. The SEO showed that in the exchange of cross-regional migrants between the South and the rest of the country, the South had suffered a net loss of black migrants aged 17 and over in every educational category. The losses tended to decline with increasing education but so too did the volume of movement. Net losses among blacks who were 50 years old and over in 1967 numbered more than 800,000 and three-fourths of these had completed eight years or less of schooling. For persons 30-49 years old in 1967, for whom educational levels were higher, the overall regional loss totalled nearly a million, a third of whom had eight years or less of schooling.

Region of birth data for 1970 reenforce these findings and show that the South had exported at least a quarter of its least educated blacks. In 1970 these out-migrants comprised more than half of the older black population with less than eight years of schooling living in the North. These figures are minimal estimates because there was a large nonreporting of place of birth and there is evidence as well that Southern birth is underreported for blacks. (Monk and Warshauer, 1978)

Although the migration data show clearly why the least educated cohorts declined so sharply, they do not explain why the numbers at the upper levels of educational attainment increased. Retention figures for higher educational categories, where the cohorts were smaller, were lower than for those less educated. And, though Northern-born black in-migrants to the South had higher educational levels than those who left the South, their numbers were small in 1970. Similarly, as Long and Hansen (1975; 1977) have shown, return migration to the South was more likely for the better educated but the numbers were still small.

Migration trends for blacks have been changing since the 1970's, and the South has begun to attract well-educated blacks, particularly to places like Atlanta and Washington, D.C. (see, for example, Myerson, 1987) Unfortunately, detailed data to examine this were not readily available. Recent migration data for the South for 1980 indicate that at least 97 percent of blacks over 45 were living in the region in both 1975 and 1980 and at least 95 percent were born in the South. Given the small numbers of college trained blacks of all ages beyond 25 who moved to the South between 1975 and 1980, it is unlikely that in-migration of well-educated older blacks accounted for the changes in the educational distributions.

Conclusions

The relationship between education and survival is an important one both for policy formulation and for research. The preliminary findings reported here, based on fairly simple measures, indicate that there is a clearcut inverse relationship between the two, both for the United States as a whole and for the South. Given what we know about the socio-economic status of poorly educated blacks in this country over the last half century, the sharp declines in numbers for those with the least education were expected. What were not expected were the changes in the numbers of older blacks who were high school graduates or who had been to college. Not only had these educational cohorts experienced favorable survival but they had actually grown in some cases. This phenomenon of growth was not an isolated one but was widespread among the five year-sex-education specific cohorts and over different time periods. The question then is where did these better-educated blacks come from and is a similar change occurring among other racial and ethnic groups in other parts of the country.

This paper started out to be a simple demonstration that increases in educational attainment levels, shown by changes in educational distributions, observed among older blacks, especially in the South, were a product of higher rates of survival among the better educated. It revealed instead that the relationship is not so simple and we are left with what the King of Siam termed "a puzzlement". One obvious conclusion to be drawn is that more research is needed. More refined measures of survival could be used and a closer examination made of the effects of changes in census procedures and coverage.

Certainly, the South, as defined by the Census Bureau (or anyone else), is no monolithic region and drawing conclusions about "the South" can be misleading. What is true for Atlanta or Washington, D.C. may bear little resemblance to the situation in rural Georgia or Mississippi. Educational attainment studies in particular are affected by these broad disparities. Whether the increases in levels of education which were found for the South as a whole obtain in its various components is worth examining.

Studies of rural areas in the South are especially needed. By 1967, according to the SEO, half the adult blacks who had lived in the rural South at some time before their sixteenth birthday, were living outside the rural South. Half of those who left, left the South altogether but the other half had taken up residence in the urban South. Blacks who migrated within the South, especially those from rural to urban areas, were less well educated than those who left the region but they were still better educated than those who remained in the rural South. As a result, the older blacks who lived in the rural South in 1967 were among the least educated people in the country and they were beset with numerous handicaps as well. (Lee and Bowles,1974) Little had occurred between 1967 and 1980 to improve the situation of elderly blacks in the rural South. Whether the elderly cohorts with the least education in the rural South were declining more rapidly than their cohorts with equally little education elsewhere needs to be explored.

In addition to studies of the rural South itself, comparisons need to be drawn between blacks living in rural areas and those living in various kinds of urban areas to ascertain whether what appear to be educational differences in survival are not in reality rural-urban ones. Blacks, and for that matter whites, are not randomly distributed throughout the country with respect to education and these distributional effects need to be disaggregated.

Finally, it may also be necessary to entertain the possibility that changes observed for education are the result of simple status enhancement resulting from pressures on the individual to increase educational attainment, if only nominally, in a society where the virtues of higher education are given so much lip service.

NOTES

(1) All census data cited in this paper are from the published volumes of the 1940, 1960, 1970 and 1980 Censuses. Data for the South for 1940 and for 1960 are for nonwhites and include small proportions of nonblacks.

(2) Data from the 1967 Survey of Economic Opportunity are from unpublished materials from the University of Georgia-U. S. Department of Agriculture cooperative project, Poverty Dimensions of Rural-to-Urban Migration.

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Second Plenary Session

Data for Public Policymaking

DATA FOR AN AGING POPULATION

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CATASTROPHIC COSTS AND LONG-TERM CARE: WHAT IS TO BE DONE?

Joshua M. Wiener, The Brookings Institution

No other part of the health care system generates as much passionate dissatisfaction as does the financing and organization of nursing home and home care costs for the elderly. Nursing home costs, which can easily exceed $22,000 a year, are by far the leading cause of catastrophic health care costs. Contrary to the belief of most elderly, Medicare pays for only 2 percent of nursing home services; private insurance pays another 2 percent. Frequently, nursing home patients must use their entire life savings to pay for their care and once totally impoverished depend on Medicaid. Public expenditures for nursing home and home care for the elderly will exceed $20 billion in 1988 and are increasing rapidly. The problems are great now and will prove to be greater in the future. Projections of current age/sex nursing home utilization rates suggest that there may be four times as many elderly in nursing homes in 2040 as there were in 1980.

In his recent report on catastrophic health care costs, Secretary of Health and Human Services Otis Bowen recommended relying solely on private sector approaches--such as private long-term care insurance and individual medical accounts for long-term care--to solve the problems of catastrophic health care costs and rising public expenditures. While expansion of private sector financing mechanisms is highly desirable, the research that we have done at Brookings Institution strongly suggests that they cannot be the total solution.

Even with extremely generous assumptions on who would participate, private sector approaches are very unlikely to be affordable by a majority of elderly, to finance more than a modest proportion of total nursing home and home care expenditures or to have more than a small impact on Medicaid expenditures and the number of people who impoverish themselves down to Medicaid financial eligibility levels. For example, by the year 2018, private long-term care insurance may be affordable by 26-45 percent of the elderly, may account for 7-12 percent of total nursing home expenditures and may reduce Medicaid expenditures and the number of Medicaid nursing home patients by 2-5 percent.

Private sector options have a limited impact because they are too expensive to be affordable by most elderly and are flawed by limits that reduce the amount of financial protection that they offer. For example, most private long-term care insurance has prior hospitalization requirements, pre-existing condition exclusions, age limitations on who may purchase policies and reimbursement levels that do not increase with inflation. The difficulty is that improved insurance coverage and affordability are tradeoffs. That is, coverage improvements are likely to make products more expensive, thus reducing the number of people who can afford them.

The limitations of private sector options leaves two broad alternatives. One is to more or less muddle along with the financing system that we have now, preferably with a variety of modifications to make the current system less onerous. High on my list of desirable modifications are increases in the Medicaid personal needs allowance, raising the level of protected assets, eliminating spousal impoverishment, and prohibiting states from forcing sale of the home. Despite its many deficiencies, the current dependence on the Medicaid program is not all bad. It is probably the least expensive possible public program and provides a safety net for all elderly. The problems with this approach are that it does nothing to prevent the elderly from becoming impoverished and does nothing to ease the forthcoming substantial financial burden on the working population once the baby boom population needs long-term care (i.e., 2040).

The other alternative is some form of public insurance program, most likely through expansion of the Medicare program. In my view, only the public sector can meet the basic needs of the vast majority of elderly. Moreover, the costs of such a program need not be overwhelming, especially if we build up financial reserves to pay for the baby boomers as we are doing with Social Security. An annual 2.8-3.0 percent payroll tax (employer and employee combined, no salary cap) would pay for a generous expansion of Medicare nursing home and home care benefits and all Medicaid long-term care expenditures. By means of comparison, it would require 1.6 percent of payroll to finance the current program of Medicare and Medicaid expenditures. The payroll tax can and should be further reduced by charging the elderly premiums, an income tax surcharge, and more extensive estate taxes.

In order to solve the problems of long-term care, we need a two-tiered public/private approach that is similar to the relationship between Social Security and private pensions. On the first tier, we need an expanded public insurance program that will provide a modest degree of financial protection for everyone. Like Social Security, the program should provide a floor which prevents individuals from becoming impoverished. On the second tier, private sector financing mechanisms, like pensions, should fill in the gaps and provide a higher level of financial protection for those who want it. It is likely that the use of private sector financing mechanisms will substantially increase in the future and that is all to the good.

The proposals by Secretary Bowen to improve the protection against catastrophic health care costs by expanding Medicare coverage are a step in the right direction. However, limiting that protection to hospital and physician costs leaves the gaping hole of nursing home and home care expenditures that even a vastly expanded private sector cannot fill by itself. A combination of an expanded public insurance program and supplemental private initiatives provides the best hope of providing protection against catastrophic costs.

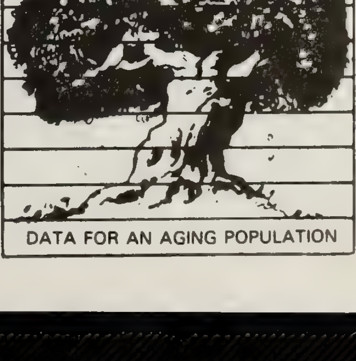
BIOMEDICAL RESEARCH ISSUES AND HOW THEY AFFECT PUBLIC POLICY

Robert N. Butler, M.D.
Mt. Sinai School of Medicine

(Not available for publication)

Session I

Quality of Life


DATA FOR AN AGING POPULATION

RESEARCH ISSUES IN QUALITY OF HEALTH CARE

Feather Ann Davis, Ph.D.

Background

The purpose of this paper is to outline some of the issues which currently are being identified as research priorities in the measurement of quality of health care. However, before I do, I want to put these current priorities into context. The present day interest in the measurement of health care quality is not new. About 25 years ago, there was a growth of health services research interest in (1) the measurement (assessment) of medical/health care quality, and (2) the assurance of quality of care. The studies included: comparison of mortality and morbidity rates for selected populations; studies of processes of care in hospitals, clinics, offices; and studies of patient outcomes of care.

At the same time the legal system was expanding the definition of hospital and physician liability and Congress was looking for a mechanism for the review of the quality and the utilization of Medicare reimbursed health care. PSROs were authorized in 1972; PROs were authorized in 1982, to replace PSROs. Since the passage of the PSRO and PRO programs, a great amount has been written about quality assurance and quality assessment. However, the quality of this "flood" of work has been mixed. Despite the large volume of writings, the conceptualization of and instrumentation of measurement of health care quality have not changed much since the the status during the early 1970s.

Conceptual Framework:

Over the years Avedis Donabedian has proposed a conceptual framework which is used by most researchers in the area and is often described simply as Structure, Process, and Outcome. Donabedian has proposed an integration of the dimensions of quality and analysis through an emphasis on the need to adequately conceptualize the components of health, including: physical-physiologic function, psychological function, and social function; levels of aggregation and organization of the providers of care; and levels of aggregation of the actual or potential recipients of care. The resultant three-dimensional cube illustrates the number and breadth of foci which are necessary in order to fully assess the many facets of medical and health care quality. These include both patient-based and population-based analyses of physiological, psychological and social functioning.

Using Donabedian's conceptual cube, we can see major gaps in the the research conducted to date. Most of the hospital and regional levels of peer review involve the review of the individual patient record, the care provided primarily by an individual physician, in a given hospital, during a single admission or episode. Most quality assurance activities conducted in hospitals across the country involve in-depth review of individual patient care. These review activities do not routinely contribute information to larger data bases upon which generalizable or comparative studies can be conducted.

The process-oriented review of quality from patient medical records, while vitally important, is very expensive: regarding patient and provider confidentiality procedures, personhours of skilled abstractor labor necessary; and political capital necessary to achieve agreement that reviews should be undertaken.

Little research has been done on the psychological and social functioning aspects. These analyses can be aggregated at various levels: individual providers, groups of providers, types of providers, individual institutions (hospitals, nursing homes, clinics, offices) and for entire populations (US and Canada and subpopulations, such as the elderly, the young; whites, blacks, etc.).

Limitations Due to Lack of Data

In 1965 the Federal and State governments became actively involved in health care cost and quality discussions; during the 1980s the major health care consumers joined the debates. As these purchasers of health care, (insurers, corporate employers, unions, and governments (federal and state)), have faced rapidly escalating costs resulting from years of high health care sector inflation, they have increasingly begun to become concerned with the quality of the care received for the money. Also, as fiscal tightening has become more prominent, and as capitated alternatives have become increasingly available, purchasers have shown more concern about possible decreases in quality. Increasingly, consumers want to know what quality of care they are buying. Consumers are demanding more data which reflect the quality of care.

Progress in the measurement (assessment) of health care quality has been impeded by (1) the lack of agreement about the appropriate indicators of good health care and (2) the lack of data bases which provide sufficient detail on the condition of the patient and description of the care provided. As with all research, the readily available health care data do not always adequately measure the desired theoretical concepts. "Quality of care" analyses are often limited to those aspects for which data exist or which are relatively inexpensively obtainable. While hospital discharge abstract data bases have facilitated analyses of patient length of stay and patient-based mortality and readmission, these are admittedly either poor proxies for "quality" or they are ambiguous regarding interpretation.

Dr. Carol McCarthy, President of the American Hospital Association, has raised the question of how "good" quality of care data have to be to be usable? A related question raised recently by Dr. Robert Brook asks--"Will imperfect information about health care quality lead to better health or will it lead to increased social divisiveness?" Brook has stated that a quality of care information system should be population-based, cover most diagnostic and therapeutic procedures, use valid measures of patient outcomes, be updated regularly, and be part of a flexible system. Currently no data bases in the United States meet Brook's criteria, or include all of the elements necessary to do all of the types of quality of care review encompassed in Donabedian's framework.

One needs to know the size and location of the population, plus know the location and nature of health care delivered to the population. In order to be able to interpret health services utilization information, one also needs to know and adjust the analyses for the characteristics of both patients and the rest of the population. Most health insurance company administrative claims data bases are limited by lack of information about the covered population. While one can learn a great deal by estimating national health status and functional limitations and disability from surveys, the expense of surveys precludes knowledge of patient health status at state or county or hospital levels.

Some state-mandated hospital cost review commissions have established statewide hospital discharge data bases which include abstracts on all patients, regardless of insurer. The Medicare administrative data system is essentially a population-based system, since all but a small proportion of persons over 65 years of age are covered by Medicare. Researchers and administrators are becoming aware of the potential of the Medicare data system for both patient-based and population-based analyses.

A great deal of research activity has been spent over the past few years to develop ways of adjusting hospital-level aggregated data for differences in case-mix, but less has been done to develop ways to measuring the physiologic characteristics of the individual patient. A few of the efforts in the development of such measures include: computer-based disease staging which was developed by SysteMetrics and has been found to be useful for certain clinical conditions; Medisgrps which was developed by InterQual and has been found to be useful in identifying important events and patient characteristics; and Apache II which was developed by George Washington University Hospital and has been successfully used in studies of intensive care units.

Research Directions

Over the past year the Health Care Financing Administration has engaged in a number of discussions regarding quality of care measurement, data development and release, and research priorities.

In June 1987 HCFA convened a Quality of Care Research Symposium for detailed discussion of the current status of quality of care research and identification of research needs. The overriding theme heard throughout the discussions of researchers was that no one measure is adequate by itself.

While there is need for analysis of the appropriateness of clinical decision-making, there is also clearly a role of population-based analyses of population health status, mortality, morbidity, disability and health care utilization which is independent of the adequacy of the medical processes employed by health care practitioners. It was clear that there is a need for several levels of analysis and monitoring. There is a need for the larger scope epidemiologic monitoring of patient outcomes such as mortality, morbidity and disability and there is need for local area analysis for identification of problems in both patient outcomes and health care processes and there is clearly a need for institution/medical care plan level analysis and monitoring of both the outcomes and processes of care.

The need for more uniform reporting of data was another common plea. In particular, there is need for more uniform reporting of patient characteristics. Development in the following areas was considered high priority: a global measure of patient physiologic status measure of physiologic reserve reliable determination of patient prognosis (likelihood of responding to treatment) and a measure of the intent of care (curative, or palliative). Donabedian has noted that these types of measures do not represent "quality", but are important for interpretation of other process and outcome measures.

There is also clearly a need for information on all sectors of health care, not just acute inpatient care, but including ambulatory care in physician offices, home health care, and nursing home care. In particular, given the increasing interest in health maintenance organizations and other forms of capitated health care payment, there is a strong demand for information on both the capitated and fee-for-service sectors. Dr. Mark Blumberg emphasized the need for measures and data collection which permit analysis of comparability across provider types and across larger health care systems.

There is also a need for more analysis of the quality of care provided to specific populations and sub-populations. Concern was raised that cost savings may motivate providers to discriminate in the types of patients accepted and in the types of care provided.

Among the perceived high priorities of the researchers at the June meeting, there were strong recommendations for the following:

- o the cataloguing and describing of existing quality of care review techniques,
- o The development of uniform data reporting,
- o the linkage of existing data,
- o the expansion of analysis of currently available data,
- o return data and analyses to health care providers so that they can review it, study it, and take action upon it, and
- o when trying to interpret incomplete "quality of care " data, exercise the greatest of caution regarding interpretation.

Currently there are no "quality of care" data bases on regional, state or federal levels. But as the pressure for comparable information on health care "quality" measures increases in order that consumers can make enlightened decisions regarding selection of individual providers, health care plans, and insurance packages, there will be increased pressure for better, comparable data bases.

Discussion

Researchers, practitioners and purchasers of care are beginning to agree about the desirability, even imperativeness, of information on attributes felt to reflect aspects of quality in health care. This heightened awareness, even impatience of many, is bound to be useful in the process of further developing and refining of measures, data bases, analytic skills of all concerned parties, and routine monitoring mechanisms. It is hoped that these refinements will ultimately improve the quality of health care and improve the utilization of resources, without producing the social divisiveness feared by many.

While there is reason for concern by health care providers regarding the effects that incomplete data can have, there is also felt to be good reason for moving ahead with thoughtful measurement, analysis and feedback. The health of the Medicare and Medicaid populations, and the American public in general, is of such importance that providers, consumers, insurers and government must work together constructively to assure and improve the quality of health care provided.

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FUNCTIONAL STATUS AND PERCEIVED QUALITY OF LIFE AMONG OLDER PERSONS

Jean E. Kincade-Norburn, University of North Carolina
Donald L. Patrick, University of Washington
Shirley A. Beresford, University of Washington
Jane S. Stein, University of North Carolina

This paper reports a study that is part of a larger project entitled "The Cost and Effectiveness of Medicare Reimbursement for Preventive Services" funded by the Health Care Financing Administration. The opinions expressed in the paper are those of the project team and do not necessarily reflect the opinions of the Health Care Financing Administration.

The objectives of the larger project are to assess the costs and changes in health status associated with the introduction and reimbursement of clinical screening services and health promotion services for Medicare beneficiaries aged 65 and older. Clinical screening services include health examination and feedback while health promotion services include individual counseling and self-help groups.

During the first year of the project 4000 beneficiaries will be enrolled for random allocation to clinical screening, health promotion and usual care groups. Patients come from primary care practices in the North Carolina Triangle area of Durham, Raleigh and Chapel Hill.

Five measures of health-related quality of life were included in the interview. The purpose of the present analysis was to examine whether or not it is necessary to include all of these measures in an assessment of the well elderly. The objectives of the paper are:

- to describe the health-related quality of life of Medicare beneficiaries
- to examine the relationship among different measures of health related quality of life in this sample
- and to discuss the relative merit of each measure for assessing health-related quality of life of older persons.

Methods

A sample of 496 beneficiaries interviewed in the first year of the demonstration, which began in late 1986, was selected randomly from approximately 1000 interviews completed to date. Each interview took approximately an hour.

The mean age of the sample was 73 years with a broad distribution across the ages. Sixty-three point four percent were between 65 and 74 years of age but there were 3.2% who were 85 or older. Sixty point seven percent of the sample were female and 39.3% were male. Sixty nine percent of the sample were white and 31% were black. The majority (54.5%) were married while 35.2% were widowed. Very few had never been married. Educational attainment and the income distribution of the beneficiaries were peculiar to the North Carolina sample with an overrepresentation of low and high income and education groups. Forty-two point six percent had less than 12 years of education while 23.6% were college graduates. Fifty- nine percent of our sample had incomes of $10,000 or over while the remaining 41% had incomes below $10,000.

Five measure of health-related quality of life were included. These were:

- the Quality of Well-Being Scale or QWB,
- the Perceived Quality of Life Scale or PQOL,
- Instrumental Activities of Daily Living or IADL,
- Current Health Perceptions,
- Self-Perceived Health Status.

Analysis and Results

The QWB was developed by the late J.W. Bush and colleagues in New York and San Diego (Anderson and Moser, 1985). The QWB scale combines preference-weighted measures of symptoms and functioning to provide a numerical point-in-time expression of well-being which ranges from 0 for death to 1 for asymptomatic optimal functioning. There are 4 components of the QWB. The first component is made up of 23 symptom /problem complexes along with their preference weights. One example of a symptom problem complex is "headache, dizziness or ringing in ears," another example is "cough, wheeziness or shortness of breath." Utilization of these symptom problem complexes does not require any assumptions about the intensity or duration of symptoms and problems, nor about underlying pathology, if any. The measure simply requires information about the symptom's presence or absence on a given day. The QWB also involves 3 scales of function: mobility, physical activity and social activity. Information about each of these 4 components is collected for the previous 4 days. Preference weights are associated for each component for each day. These weights had been determined by those developing the scale. They asked a random sample of adults living in the community to evaluate the desirability of a number of health conditions. An average preference weight is calculated for each component and for the overall QWB.

Figure 1 shows the mean overall and mean component scores of the QWB. The overall mean deviation from 1 was derived by summing the mean deviation scores of the components. Most of the deviation in the overall QWB came from the symptom /problem complex, while the mean scores for mobility, physical activity and social activity were high. Since the sample was a relatively well, ambulatory group, it might be expected that these high scores for the mobility, physical activity and social activity components would be found.

The Perceived Quality of Life scale was developed by Donald Patrick and Marion Danis at the University of North Carolina at Chapel Hill (Patrick et al, 1987). This is a 12-item scale that provides individual and overall scores of items describing satisfaction with health, satisfaction with sexual activity, satisfaction with social and economic status, and satisfaction with self-worth. Each item is scored 0 to 100, with an overall average score ranging from 0 (equal to very dissatisfied) to 100 (equal to very satisfied). A factor analysis was done on the PQOL items; the 3 factors that were found were labeled satisfaction with health, satisfaction with social and economic aspects of life and satisfaction with self-worth. The item concerning satisfaction with sexual activity did not fit with any of the factors and so was kept as a separate item.

Figure 2 shows the mean overall and profile scores for the 12 items on the PQOL. The profile scores ranged from a low of 70.5 for satisfaction with sexual activity to a high of 88.6 for satisfaction with how respected they were by others. Overall scores ranged from a minimum of 20 to a maximum of 100 with a mean of 79. In general, the elderly in the sample appeared, on the average, to be relatively satisfied with most aspects of their lives.

The indicators for Instrumental Activities of Daily Living were developed by Lawton at Philadelphia and also investigators at Duke University, and have been used by a number of others. The version chosen for this study was used in the National Center for Health Statistics, National Health Interview Survey, Aging Supplement in 1984 (National Health Interview Survey, 1984). It is a measure of performance of 6 areas of self-care: doing heavy housework or yardwork, shopping, cutting toenails, managing money, using the telephone and preparing meals. Each area is scored 0 to 3 where 0=no help, 1=some help, 2=a lot of help and 3=unable to do. The overall average score ranges from 0 which is equivalent to no help needed in any of these areas of self-care to 3 which is equivalent to unable to perform any of these areas of self-care.

The distribution of the mean instrumental activities of daily living scores was quite skewed with the majority of the sample having mean scores between 0 and .99 which indicates they needed little or no help with the 6 self-care activities. The mean scores ranged from a minimum of 0 to a maximum of 2.33.

The measure of Current Health Perceptions was developed by Allyson Ross-Davies and John Ware at the Rand Corporation (Ware et al, 1978). It is a measure of the respondent's perception of his or her general health at the present time and is part of a larger Health Perceptions Questionnaire. It is comprised of 4 items, each item scored on a scale of 1=definitely true to 5=definitely false. An overall average score ranges from 1 to 5 where a low score indicates poor perceived health and a high score indicates good perceived health.

The distribution of the mean current health perceptions scores shows that the largest percentage (36.4%) perceived their health as being good. However, 17% perceived their health to be quite poor.

Self-Perceived Health Status is a global measure of the respondent's perception of his or her health. The question is asked, "Would you say, in general, your health in the last month has been excellent, very good, good, fair or poor?" A low score indicates good perceived health and a high score indicates poor perceived health. This is a very simple measure which has been included because it has been shown to be a good predictor of future health status and mortality.

An even wider variation of response was found for Self-Perceived Health Status than with the measure of Current Health Perceptions. Here, although 40% perceived their health to be very good or excellent, 30% or nearly one-third of the sample rated their health as only fair or poor. Therefore, although the QWB and IADL scores indicated a relatively functionally independent group, this measure and the mean Current Health Perceptions indicated that fairly large percentages perceived their health to be only fair or poor.

Correlations were computed between the overall and component scores of the QWB and the overall PQOL and the 3 factors. Because of the sample size, all the coefficients were significant when they reached a value of 0.1. The highest correlation appeared to be between the overall QWB and satisfaction with health measured on the PQOL and this correlation was only 0.32. Indeed, even though many members of the sample had good functioning (as measured by the QWB) they were not necessarily satisfied with their health and other aspects of their lives. The size of the correlations was evidence that the PQOL was measuring something different from the QWB.

Figure 4 shows a correlation matrix of the 5 measures of health-related quality of life. For the purposes of this paper the variables were re-scaled so that a low score represents poor health and a high score represents good health and so all the coefficients are positive. Again because of the sample size, all the coefficients were statistically significant. It appeared that the highest correlation was between the measures of Current Health Perceptions and Self-Perceived Health Status. All the other measures, and in particular the PQOL and QWB, were not highly related to one another.

Finally a factor analysis was performed that included the 5 overall measures of health-related quality of life and the components of the QWB and PQOL. Six factors emerged. Figure 5 shows the eigenvalues of the factors and the variables in each factor which had the highest factor loadings. The first factor after rotation gave high loadings to PQOL overall and its components, and confirmed that this was a distinct measure. The second factor gave high loadings to the QWB overall and the Symptom/Problem Complex component of the QWB. The third factor was a combination of Self-Perceived Health Status and Current Health Perceptions, which went together as discovered from the correlation matrix. It appeared that the QWB was separable into three components, with the overall QWB going with its CPX subcomponent. IADL stood alone, and indeed could be omitted without losing too much of the potentially explainable variability in health-related quality of life measures for this sample. All the 6 factors together explained 84% of the overall variance. If the factor containing the IADL were dropped from the analysis, 76% of the variance would be explained by the remaining 5 factors.

Conclusion

In conclusion, it appeared that:

- the measure of Self-Perceived Health Status was a powerful discriminator on its own.
- the PQOL was a distinct measure to explain the variation of health related quality of life.
- the IADL did not add much to explain the variability of health-related quality of life for this healthy sample of elderly.
- the QWB, in the factor analysis, had separate components in this healthy sample of elderly and thus the QWB components should be reported along with the overall score.
- that respondents reported that they were functionally well did not mean that they were satisfied with their health or other aspects of their lives.

Overall, then, it could be concluded that, perhaps with the exception of the IADL, all these were separate measures and if any were eliminated from the analysis part of the picture of health-related quality of life would be missed.

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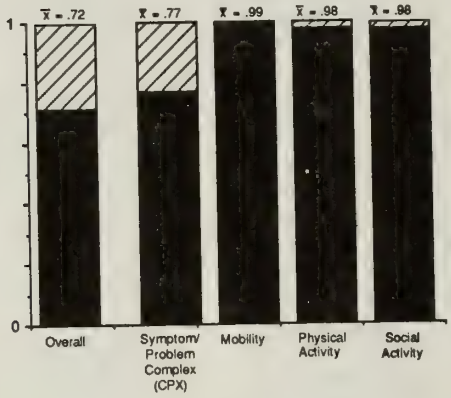
Figure 1

Mean Overall and Component Scores on Quality of Well-Being Scale for 494 Medicare Beneficiaries



Mean Overall QWB and Component Scores

Figure 2

Mean, Overall and Profile Scores on Perceived Quality of Life Scale

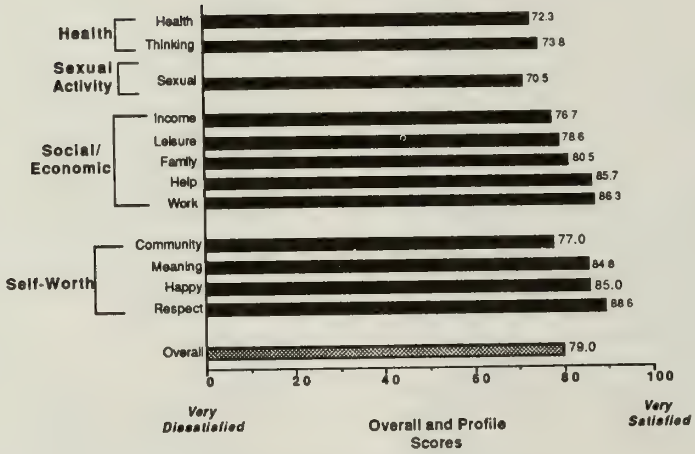
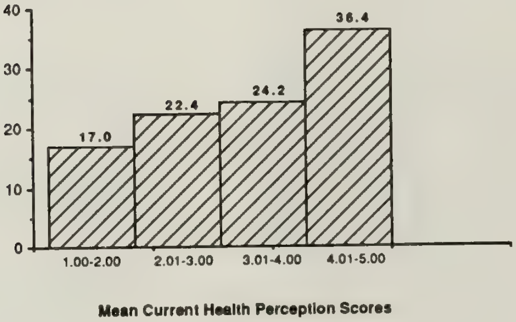


Figure 3

Distribution of Mean Current Health Perceptions Scores for Medicare Beneficiaries



low score indicates poor health
high score indicates good health

Figure 4

Correlation Matrix of Five Measures of Health Related Quality of Life in Medicare Beneficiaries

	PQOL	CHP	SPHS	IADL
QWB	0.18	0.43	0.34	0.43
PQOL		0.33	0.28	0.24
CHP			0.68	0.43
SPHS				0.36

Note: Sample sizes vary between 440 and 493

Figure 5

Health Related Quality of Life Measures: Groupings of Variables as Indicated by Factor Analysis

Factor Eigenvalues	*Variables with highest loading in each factor*	
2.6	PQOL Overall PQOL Social/Economic	PQOL Health PQOL Self-Worth
1.9	QWB Physical Activity	QWB Social Activity
1.9	SPHS	CHP
1.7	QWB Overall	QWB Symptom/ Problem Complex
1.7	QWB Mobility	
0.9	IADL	

MEASUREMENT OF COPING STYLES IN THE ELDERLY

Lynda Powell, Anita Roth & Kitty Gelburg, Epidemiology, Connecticut

INTRODUCTION

This paper presents an overview of a pilot study conducted to develop a questionnaire to assess coping styles in the elderly. The focus of this paper is on the methodology used in developing the questionnaire. Thus only a select literature review is presented, and doubtless some seminal works in the area of coping are excluded.

With the aging of our population, increases in life expectancy, and the projected increases in the demand for health care services, research is being directed toward understanding what keeps people healthy despite advancing age. Given the projected increases in life expectancy, the goal is to maximize an individual's quality of life: both physical and psychological health. It is important, therefore, to identify factors associated with improved quality of life and health. A range of factors associated with physical health have been studied. Psychological resources may also play an important role in health, although they are more difficult to measure. It is possible that psychological resources play a role in mediating the effects of life events and stresses.

Studies assessing the impact of major life events on the elderly are limited to an evaluation of their impact on mental health or self-reported physical health (2, 10, 19). Although positive associations have been observed, these results are difficult to evaluate since the frequency of major life events has been observed to decrease with age (3, 9, 11, 14, 30) and this decrease raises questions about the appropriateness of the methodology for measuring life events in elderly persons. Even if life events assessment technology was found to be appropriate for use with elderly persons, it is questionable whether or not environmental strains would be able to account for more than nine percent of the variance in health status which is the amount accounted for by life events in middle-aged populations (20).

Minor life events may be more relevant than major life events to health-related coping since they are proximal measures of repeated and chronic strains (4). In younger groups, hassles have been found to be more predictive of physical health status than major life events (4) and in the elderly they have been associated with self-reports of physical symptoms (10).

In general, regardless of the presence of major or minor life events, some elderly people manage poorly and some manage well. This has led to the study of mediating factors which cushion the impact of environmental strains on the experience of stress and the development of disease.

Several different approaches have been used to study mediating psychological factors. One approach is to study personality predispositions, such as locus of control (16, 26). Another approach is study of behavioral coping styles. This approach assumes that these behaviors represent a style of responding to stressors, which, over time, exerts a direct pathophysiological impact on health outcomes. An example of a behavioral coping style is Type A behavior (7). A third approach to the study of mediating factors between stress and health outcomes is to study behavioral coping in response to specific stressors. In this approach, subjects who are undergoing the stressors are observed to detect individual differences in response, and to link these differences to various indices of adaptation. However, the stressors most often studied are usually major life events, and for the most part unexpected. Thus strong reactions such as shock, disbelief, and anger are to be expected.

Two important theories of coping are the following: Using a sociologic-person-environment interactional perspective, Pearlin and Schooler (18) conceptualized effective coping strategies as those that were able to prevent hardships from resulting in emotional stress. Lazarus and colleagues (15) have presented a more elaborate psychological theory of stress and coping which is also grounded in the person-environment interaction. Two key features of their theory are that stress is relational and bidirectional, that is, stress is a relationship between the person and the environment that is dynamic and constantly changing over time. Coping serves two major functions. Problem-focused coping serves to manage the problem causing the distress and emotion-focused coping serves to regulate the emotions themselves. The relative proportions of each type of coping varies with specific appraisals but some evidence does exist that the greater the perceived control, the greater the use of problem-focused coping, and the less the perceived control the greater the use of emotion-focused coping (5).

One theme that appears important and consistent through the literature is the importance of the perception of control. In an elderly population the perception of control may be especially important. Older persons may experience losses in areas where they formerly had control (23). Evidence for a link between control and health in the elderly comes primarily from experimental manipulations believed relevant to control, such as forced relocation (12, 28), increasing the number of choices one has over daily events (13, 24, 27, 29), and training in stress reduction aimed at increasing control and mastery over daily stressors (22, 10). Although there are difficulties associated with studying the health implications of control, there is evidence that control may be important to health. If one assumes that healthy coping in the elderly is directed towards a maintenance of the perception of control over various aspects of one's life, despite losses, then it becomes important to specify how this could be done.

A useful model for a determination of control enhancing coping is the 2-process model of perceived control formulated by Rothbaum and colleagues (24, 31). This model suggests that individuals assume control over events either by bringing the environment in line with their wishes (termed primary control) or by bringing themselves in line with environmental forces (termed secondary control).

Another type of coping response distinct from primary and secondary control responses are responses which can be classified as representing uncontrollability. This category of responses includes two types of responses: 1) continued struggle with the problem, or 2) giving up. Uncontrollability responses are distinct from secondary responses. An example of a response that can be characterized as use of secondary control would be "I can't change the situation so I'll accept it." The person is changing his interpretation of the situation, thus averting distress. In contrast, a response characterized as uncontrollability would be "I give up." The individual does not change his perception of the situation. Therefore, a useful distinction between secondary control and uncontrollability is that the individual using secondary control controls the meaning of an event before it gives rise to distress, while with uncontrollability this does not occur.

Perceived control also appears to play a role in behavioral patterns such as learned helplessness and Type A behavior. Learned helplessness, as conceptualized by Seligman and colleagues, associates helplessness with the presence of an uncontrollable stressor and a perceptual style that an individual's efforts will have no effect on outcome (1). Type A behavior has been interpreted by some as a style of coping with the threat of lack of control (8, 15).

In developing the Elderly Coping Questionnaire the focus was on studying coping responses in terms of perceived control. As described in more detail in the methods section, the Elderly Coping Questionnaire consists of brief descriptions of problem situations. Subjects were asked what action they would take in each situation and responses were classified in terms of the type of control employed (primary, secondary or uncontrollability).

METHODS

MEASURES

The Elderly Coping Questionnaire was developed in two phases. The first phase involved a series of open-ended interviews. The purpose of this phase was to develop a picture of what events and situations occurred commonly, and were important to the elderly, and how they dealt with these situations. The second phase involved development of a more standardized format for the interviews.

Open-ended interviews - Phase 1 Open-ended interviews were conducted with 33 individuals (see Subjects section below). These interviews involved open-ended questions about what changes, losses, problems or conflicts the subjects had experienced in the past six months to one year. After the individual described the problems or situations, interviewers asked what was felt to be the cause of the problem, what action was taken, and how, or if, the problem was resolved. These interviews provided a picture of what situations were common, and considered important by the respondents.

Revised interview - Phase 2 Using information from the open-ended interviews, a more structured and standardized interview was developed. The focus of the questionnaire was to assess efforts to maintain or relinquish control in a variety of situations. Twelve specific situations were described. These situations were of three types: interpersonal situations, situations that could best be characterized as losses and "other" situations. Examples of interpersonal situations include "A friend acts coolly towards you," and "You cannot see your children as often as you would like." An example of situations characterized as losses is "You cannot hear what your spouse is saying" (hearing loss). "Other" situations include descriptions of financial difficulties, and description of a mugging. Situations were included that occurred commonly to members of all age groups, as well as some that were more likely to occur to the elderly.

In order to assess how people would react when under stress, subjects were asked two times what action they would take in each situation. The interviewer described the problem situation and asked what the respondent would do to resolve the problem (termed first prompt). The respondents were then asked what they would do if the first action was unsuccessful (termed second prompt). Responses were categorized in terms of exhibiting primary, or secondary control, or uncontrollability.

A sample item is given below. The responses (a-d) are characteristic of the three different types of control.

Figure 1
Sample item from the Elderly Coping Questionnaire

All of a sudden, an old friend acts coolly to you. What would you do about it? (First prompt) If that doesn't work, then what would you do? (Second prompt)

a. Ask the person what was wrong
(Primary Control)
b. Give him/her time to come around
(Secondary Control)
c. Nothing. It is his/her loss
(Uncontrollable: Struggle)
d. There isn't much you can do
(Uncontrollable: Give up)

The interview also included some sociodemographic questions. Type A behavior was assessed with a modified version of the Structured Interview (6). Depressive symptomatology was assessed using the CES-D scale (21). Physical health was assessed using self-reports of chronic diseases, disability and ailments.

SUBJECTS

Subjects for this study were a non-random sample of individuals from areas in South Central Connecticut. Various senior service organizations and housing complexes volunteered their assistance in locating subjects. Subjects were interviewed either in their homes or in a senior center located near their residences. Initial contact was often made through the representative of the organization.

Interviews were conducted in two phases. Thirty-three subjects were interviewed with open-ended interviews. Fifty-two individuals received the revised interview.

The demographic characteristics of the sample are displayed in Table 1. The ages ranged from 60 to 88. Seventy-one percent of the subjects were female and 85% were white. Fifty-nine percent did not have a high school diploma. Twenty-one percent of subjects were classified as lower socioeconomic status, and 31 percent of subjects were classified as high socioeconomic status. Thirty-two percent were married, and 43 percent widowed.

Table 1
Description of Sample

	TOTAL SAMPLE	SAMPLE RECEIVING REVISED INTERVIEWS
N	85	52 (61.2%)
SEX: Male	25 (29.4%)	17 (32.7%)
RACE: White	72 (84.7%	44 (84.6%)
AGE: Less than 70	20 (23.5%	11 (21.2%)
80-88	25 (29.4%	18 (34.6%)
MARITAL: Married	27 (32.1%)	21 (40.4%)
EDUCATION: HS Grad	35 (41.2%)	24 (46.2%)
GEN'L HEALTH: Good	34 (40.5%	23 (40.1%)
TYPE A BEHAVIOR	20 (24.1%)	13 (25.5%)
DEPRESSION	19 (25.0%)	14 (29.8%)

RESULTS

The focus of this paper is the development of the questionnaire. Thus the results section will be limited to a brief discussion of some trends which appear interesting. However, the sample size is small, and all data should be considered preliminary.

One trend that appeared is the difference in type of control employed in the first prompt compared to the second prompt. In response to the first prompt, two-thirds of the responses were characterized as using primary control, and only eight percent of the responses were characteristic of uncontrollable responses. However, in response to the second prompt the proportion of responses using primary control dropped to forty percent, while the proportion of responses categorized as uncontrollable rose to 35 percent.

The difference in proportion of responses to the second prompt that were classified as uncontrollable as compared to responses to the first prompt was larger for Type A individuals as compared to non-Type A individuals. A much greater proportion of Type A individuals gave uncontrollability responses to the second prompt than did non-Type A individuals. A similar pattern was seen for depressed versus non-depressed subjects.

CONCLUSIONS

This paper discussed the development of the Elderly Coping Questionnaire. We feel that this questionnaire has three valuable aspects: 1) through the use of the second prompt it determines how the subject might react to the potentially stressful situation that might develop if his first attempt to deal with a problem is unsuccessful; 2) it includes problem situations that vary in their nature and severity; and 3) it includes problem situations that are common and important to the subjects.

A central aspect of the Elderly Coping Questionnaire is the use of a second prompt. Preliminary results suggest that there is a different distribution of responses to the first prompt as compared to the second prompt. There is a higher proportion of responses categorized as uncontrollable to the second prompt. In addition, a different pattern of responses is also seen between Type A and non-Type A individuals, and depressed and non-depressed individuals. The use of the second prompt may provide a useful means of discriminating between coping styles. Further research is being conducted to assess its merit.

A second important aspect of the questionnaire is that the situations included in the questionnaire are quite diverse. Problem situations include relatively minor problems, such as a description of situations when a sales clerk behaves in a rude manner, as well as more serious problems, such as a mugging, or financial problems. Such a diversity of situations gives a picture of how an individual acts in a variety of situations, and may enable testing of the consistency of a person's reactions over a wide variety of situations.

A third important aspect of the questionnaire is that the problem situations were derived from discussions and open-ended interviews with elderly people. Thus they reflect issues and concerns which are considered important by the elderly and occur frequently. While obviously not all situations will have been experienced by all subjects, a large proportion of the situations will reflect issues which they have either experienced or are worried about. This was reflected in the interviews. It was common for respondents to exclaim "oh, that just happened to me" after the interviewer described a situation.

These advantages suggest that this

questionnaire may prove useful. Currently, further studies are underway to assess the validity and reliability of the questionnaire.

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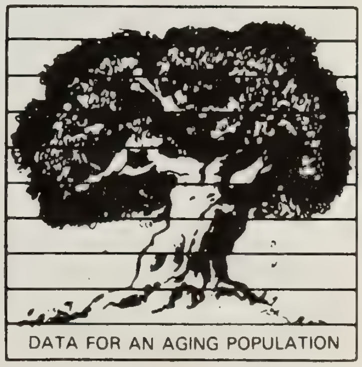
Session J

Panel on International Activities in Data and Research on Aging



DATA FOR AN AGING POPULATION

DATA ON AGING IN BRITAIN

Emily Grundy, King's College, London, UK

Comparable data sets are clearly a pre-requisite of cross-national studies of age and aging and so the focus of this presentation is on British data available from census and vital registration sources, national sample surveys and other large studies, particularly those currently being developed.

Census and vital registration data

The 1981 Census was the eighteenth in a series started in 1801 (there was no census in 1941) and planning for the 1991 Census is now well under way. Although age misreporting by the elderly was extensive in the censuses of the nineteenth and early twentieth centuries (Lee and Lam, 1983) and some errors at the extreme upper tail of the age distribution persist (Thatcher, 1981), the quality of British census data is high and under-enumeration and age misreporting are much less serious problems than in the USA (OPCS, 1984; Rosenwaike, 1981). However, less information is collected in the British census: in 1981 21 questions were asked compared with 60 in the 1980 USA Census (Redfern, 1981). A greater barrier to census based comparative studies is the fact that there is no British public use census sample. However, some recent developments have extended the scope for census based studies.

One such development is the release of individual level data from the 1891-1921 censuses for 13 communities. This is being analysed by the Cambridge Group for the History of Population and Social Structure, who are examining, among other things, changes in the living arrangements and employment patterns of the elderly during this period.

Another innovation has been the development of the Office of Population Censuses and Surveys' (OPCS) Longitudinal Study (LS). This is a record linkage study which includes micro-information from both census and vital registration sources. The LS is based on a 1% sample of the population of England and Wales enumerated in the 1971 Census. Information on demographic and health related events, such as births, widowhoods, cancer registrations, admissions to long-stay psychiatric units and deaths has been added to sample members' records from vital registration systems. More recently data from LS members' 1981 Census records have also been incorporated into the LS. LS data have now been used in a number of studies to look at mortality differentials (Fox and Goldblatt, 1982), including post-bereavement mortality (Jones and Goldblatt, 1987); household transitions in later life (Grundy, 1987a; Grundy, 1988) and retirement migration (Grundy, 1987b). It is hoped that future work will include some cross-national studies: Tony Warnes and Philip Rees in the UK plan to use LS data in the cross-national study of retirement migration, co-ordinated by Andrei Rogers of the University of Colorado, in which they are involved. There are also plans for a comparative study of the households of the elderly in France and England and Wales.

National surveys

A number of annual national surveys are conducted by OPCS. Of these, the one which includes the most information on the elderly is the General Household Survey (GHS). The GHS was started in 1971 and includes questions on household, housing and other socio-economic variables; on the use of health and welfare services and on self-reported long and short term morbidity. The 1980 GHS included an expanded section on the elderly and data from this have been used, for example, to examine relationships between functional health status, household composition and use of services (Evandrou et al, 1986). Data from the GHS are deposited in the Economic and Social Research Council (ESRC) Data Archive at the University of Essex and so are freely available to the research community.

Apart from the GHS and other annual surveys, in 1985/86 OPCS also conducted a national sample survey of disabled people, including elderly disabled people and those resident in institutions; this was the first survey of disabled people since the 1968/69 study reported by Harris (1971). The data from this earlier study have recently been deposited in the Data Archive.

Cohort and follow-up studies

There are a number of cohort and follow-up studies under way or planned which are large enough to offer opportunities for cross-national work now or in the future. Some of these are described briefly below.

(i) The Medical Research Council (MRC) National Survey of Health and Development

This is a cohort study of a sample of those born in 1946 (and so still comparatively young). There are approximately 5,000 cohort survivors who were last contacted in 1982. Data on the survival of their parents is available and is to be used in the development of models on differentials in the probability of having a surviving elderly relative. Future rounds will include tests of cognitive performance and so may prove valuable in the identification of risk factors for dementia. The study is co-ordinated by Dr. Michael Wadsworth at University College, University of London.

(ii) 1987 Prospective Study of 55 year olds in Scotland

This is one of three prospective studies of various age groups being undertaken by the MRC

Medical Sociology Unit in Glasgow, Scotland. The target size for the study of 55 year olds is 1,600. Extensive base-line data on health related behaviors, service use, functional capacity and mental health are to be collected, including physical measures such as blood pressure. The focus of the prospective study is on the interplay between health and social factors in transitions such as retirement and widowhood and on mid-life precursors of impairment, disability and handicap. The first follow-up interviews will probably be carried out within the next five years.

(iii) Health and Lifestyle Survey

This national sample survey of health and lifestyles carried out in 1984 included over 1,500 elderly people. The focus of the study is on the association between physical health and smoking, diet, exercise and alcohol consumption. An integrated psychological and mental health study is concerned chiefly with cognitive function, personality, lifestyle and reported health. Interview data on socio-economic and family details, reported health, health beliefs and health related behavior were collected, together with physiological measures and tests of cognitive function. The initial data are now available in the ESRC Data Archive and follow-up studies are planned.

In addition to these studies, six other prospective studies of health and cognitive function are under way or planned in various research centers in Britain. Discussions about a proposed national prospective study of dementia and other causes of disability are also taking place.

Service related studies

There are numerous, generally small scale, British service related studies under way or recently completed, so in this section I will refer briefly only to national studies or those which involve the Age Concern Institute of Gerontology (ACIOG) at King's College, London.

(i) 1981 Residential Homes Study

This study, conducted by the Personal Social Services Research Unit at the University of Kent, was based on a national two-stage sample survey. Information was collected about residents, including their functional health; the physical characteristics of homes; costs and the characteristics of proprietors of private homes.

(ii) Dementia Home Support Study

This is an intervention study being carried out by ACIOG and the Department of Psychiatry at Guy's and St. Thomas' Medical School. The aim of the study is to see whether the provision of extra services, principally personal care provided by locally recruited paid workers, enables at least some of those with dementia to be maintained at home rather than entering an institution. A preliminary report of interim results is available (Askham, 1986).

(iii) The Aging of Residents in Specialised Housing Schemes for Elderly People in the United States and Britain

Proposals for research into the welfare and management implications of the aging of populations resident in housing schemes for the elderly are currently being developed. It is hoped that this will be a collaborative cross-national study involving ACIOG and Professor Robert Katz of the University of Illinois.

This review of data sources and research activities in Britain is necessarily brief but it is hoped that it illustrates that there is considerable scope for cross-national comparative studies.

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THE AGING WORLD SITUATION

David M. Macfadyen, World Health Organization

Elders grow faster than total population

One of the greatest concerns of public health is the rate of growth of the world population. However, the elderly population of the world is growing faster than the total population. This growth rate will result in almost 600 million people aged 60 and over worldwide by the year 2000 and almost a billion by 2020.

The distribution of the world elderly population is also changing, with only a minority in developed regions of the world by the year 2000 and the great majority in developing regions by 2020.

By the time I reach the age of 90 (2025), there will be 10 million Britons over 65 years of age. But in 12 countries (including China, India, Indonesia, Brazil, Mexico and Pakistan) this number will be exceeded. In fact the United Kingdom will see a relatively small annual growth in the population aged 75 or over, compared to Bulgaria, the countries of Southern Europe and the new aging countries like Brazil and China.

The speed of population aging in the new aging countries is dramatic. Japan will have 14% of its population aged 65 years or over by the year 1996: 26 years before it was 7%.

The fastest growing segment, within the older population, is that aged 80 years and over. Again on my 90th birthday, Scotland, like most developed countries will have 4% to 5% of the total population in the age group 80 years and above.

Public health implications of growth

A pioneering WHO Scientific Group, on the Epidemiology of Aging, proposed that we use an epidemiological approach to meet the challenge of world population aging. Collaboration in the field of aging between the clinician and the epidemiologist was seen as the way to accelerate progress towards the goal of extending the expectation of disability-free life of elderly people.

Japan's life expectancy, at 77 years, is currently (1985) the highest in the world. Among European countries, Sweden approaches closest to this level and the value for the United Kingdom is 3 years below Japan's.

The life table is long established as a tool of public health, and expectation of life at birth is one of 12 global and some 100 regional indicators adopted by the member countries of WHO to assess their progress towards the attainment of Health for All by the year 2000.

Health inequalities in old age

As the 21st century approaches, the discipline of public health will begin to view mortality and morbidity at the upper age ranges as a measure of the health of our society in the same way that it viewed infant mortality as a proxy measure of wellbeing in the present century.

Indicators

Last offers as a definition of a health indicator "a variable, susceptible to direct measurement, that reflects the state of health of persons in a community". The use of indicators can also be linked to different aspects of health care effectiveness, for example Holland defines 'population effectiveness' as the ability of a health service intervention/programme to produce a measurable improvement in the health of the population as a whole (or in this case the health of the elderly population as a whole).

Very few studies of health and social care for the elderly focus on the outcomes of care - instead the emphasis is on descriptive studies of the organization or process of care or of aspects related to coverage, uptake and utilization.

A critical review of the literature, at the time the WHO Scientific Group on the Epidemiology of Aging met, revealed few well-conducted epidemiological studies. However, the tide is turning and, today, WHO is re-inforcing the movement to use epidemiology - the discipline of scientific reason - in the study of aging. In particular, the goals of the epidemiology component of the WHO Special Programme for Research on Aging are to:

- identify the determinants of healthy aging in different geographical situations
- support the use of the tools of epidemiology and of the social sciences in advancing the health and social status of the world's elders, and
- build health and social policies for the elderly upon a sounder foundation of data.

Maps and atlases

The International Agency for Research on Cancer has taken up the technique of mapping morbidity and mortality by geographical areas, an epidemiological practice long in use in the field of communicable diseases. Map-based data displays can equally be used to demonstrate the implications of aging for planning and management of health services.

While the earliest multicolour disease maps were hand coloured, current microcomputer technology allows maps to be drawn, and different geographical areas shaded, according to a range or cut off value defined by the data sets. This geographical information system is illustrated in the map from the European Region.

With map-linked database systems, numerical or textual data can be retrieved from a graphic of a country or its geographical subdivision.

The generation of such atlases or maps, from within country or from across-country data, has evolved from collaboration between WHO and Johns Hopkins School of Public Health and a description of the use of this as a planning tool was published in 1984 in the World Health Statistics Quarterly.

WHO health and demographic profiles of the elderly

The World Health Organization has adopted a systematic approach to health planning and management in implementing the Global Health for All Strategy, (HFA2000), the so-called Managerial Process for National Health Development (MPNHD). This MPNHD is basically a comprehensive, long-term and strategic planning approach, but it can be applied to specific problem areas, e.g., the care of the elderly. As an integral component of the WHO programme on Health of the Elderly, provision has been made for the compilation of national health and demographic profiles. These profiles are designed to assist health planners, epidemiologists, or health managers in delineating the health and social status of the elderly within a given society and to anticipate changes in health patterns and/or social support and service needs.

The profiles were developed according to the following broad principles:

- they had to be based on readily available data;

- they must be scientifically valid yet effectively communicate both the scope and nature of the health and social condition of the elderly to policy makers;

- they must be uniform so that international comparisons could be made; and most importantly,

- they should present data in sufficient scope and detail to be a useful planning tool at the country level.

Essentially, the elements fall into two broad groups:

a) basic health monitoring statistics, which give particular attention to trends;

b) statistics for the better design of health and social services.

The content of the profiles has been determined accordingly. At present, two broad sections are included:

Section A: Demography: data from various sources on population structure by sex and age and derived population ratios relating to sex composition, dependency status, etc. for the period 1950-2000; data on the aged population according to marital status, living arrangements, labour force participation and area of residence (incomplete for many countries).

Section B: Mortality: data on distribution of deaths among the elderly by sex, age and cause; trends in life expectancy and survivorship by sex and cause; age-cause of death decomposition analysis of mortality trends over the period 1960-1980. Data for this section are available for about 40 countries.

It is expected that the scope of the profiles will be expanded subsequently to include information on other aspects of direct relevance to national health development strategies such as availability and distribution of health services, morbidity and disability.

Analyses of the international mortality data base maintained by WHO could ultimately form an integral component of the profiles by helping to place the national health situation in a comparative international perspective.

Relevant WHO documents and publications

World Health Statistics Quarterly Report. Special issue on public health implications of aging. WHO, Geneva, 1982. E/F

Compilation of national demographic and health profiles of the elderly: report on a WHO meeting. WHO, Copenhagen, 1985 (IRP/HEE 115-02)

WHO Technical Report Series, No. 706, 1984. (Uses of epidemiology in the study of aging) E, F, S (our of stock), R

Svanborg, A. et al. Epidemiological studies on social and medical conditions of the elderly: report on a survey. Copenhagen, WHO Regional Office for Europe, 1982 (EURO Reports and Studies, No. 62) C, E (ICP/ADR 037) F

Map-linked data bases and visual epidemiology: report of a WHO meeting. WHO, Geneva, 1987 (HST).

ACTIVITIES IN DATA AND RESEARCH ON AGING IN JAPAN

Nobuo Maeda, Institute of Public Health, Japan

1.Measurement and data on health of the elderly

Relating to individual level of health, most popular approach is to measure the functional abilities or activity of daily living (ADL). The advanced health center or hospital afford the data and information for the elderly who used health check or health examination programs by the municipalities or non-profit organizations. In Japan, the company should afford once a year annual health check for their workers by the Labor Sanitation Law, however, this health check program used to cover the worker or employees of big business. Also, this program deals with the basic health examination of blood pressure, urine test, blood test and X-ray examination to detect tuberculoses, for example. Because the retired person is not eligible to have this opportunity, we can not find enough number of elderly in this group for measurement of health of the elderly under the company managed health program.

According to the Geriatric Health Act of 1983, every Japanese of the age of 40 years and over is able to have annual health check without charge. Even though this health check is also basic similar to that in working place, a mayor or a governor of municipality could keep whole data on that health check. If one person wishes to compare his or her current data to previous data, it is very easy to read data and information on his or her note-book which was provided freely and universally by the law from mayor. Theoretically or legally speaking, these kinds of arrangements were good and useful for our analysis of data on the health of adult and elderly. But, actual utilization rate of this health check by the Geriatric Health Act is very low so far with the level of 23.8 percent (1981) in the total eligible population in Japan. Most of adult and elderly prefer more advanced health care or health examination. And they already have been in the office of doctors concerning the some sort of illness or diagnosis of themselves. In that time, especially, the elderly of 70 years and over who is paid by the geriatric health medical care funds for their visiting, could get several health assessment continuously in the doctors' office under the law with small amount of copayment.

Another setting of measurement of health for each person could be arranged in the occasion of so-called the comprehensive health examination and health diagnosis ("human dock") mainly by the general hospitals with charge (ca.$200-400). The health insurance societies and company provide this health check for the beneficiaries or the employed person as a fringe benefit from each health insurance organizations. The individuals keep their medical or health records. Company or insurance society have no data on these check.

2. Data and information of health as a group or municipality

Each big company asks the records of health check for every newly employed person to the company. Every Japanese has medical record and invoice for medical payment (medical bill) under the scheme of health insurance and social assistance when they visit doctors and dentists or admit a hospital. In this medical bill, it is required to note the diagnosis for this utilization in each month by the specialities which the patient had taken, by notifying the services of outpatient, hospitalization and dental care.

On each medical bill, we have the data of the diagnosis including complications, length of stay, frequency of visit (day) and charges of each care or services. It is very hard to interpret these data to the incidence rate or prevalence rate. The utilization rate might be most reliable and useful data on this information. In Japan, doctors used to put many diagnosis on the medical bill for health insurance. Problem is how to find and select major diagnosis among these diagnosis.

Central government collects the data on mortality, morbidity, utilization rate of health check, physicians' visits, rate of hospitalization, and medical cost per beneficiaries or per patient for each insurance group and municipalities. In the case of municipalities, however, we can use the data of the national health insurance (NHI) mainly. The coverage rate of beneficiaries under NHI vary greatly according to locality from five percent to eighty percent, for example. The self-employed and retired people is a major group in NHI. So that, we must find new method of statistical standardization of these population for the comparative analysis of the level of health and health care among the municipalities.

3. Data of home-bound elderly and dementia

Japan is very unique country who makes the statistics of home-bound patient by the three national survey of 1978, 1981 and 1984. We expect the rate of home-bound elderly 4.2 percent in total elderly (65 years and over), by dividing to the patients in their home (2.8), hospital (1.4) and nursing home (ca.0.4 in 60 years and over). The municipal office of welfare provides special economic assistance for the care-givers; $200 per month in Tokyo. Hence, each office has to hold the latest number of home-bound elderly in every three months, at least. This data is very helpful for the planning of community care for the home-bound patients and care givers, especially in the economic and social support. We are able to estimate the need of day care, respite care ("short stay") for care-giver and home health. But the reported number of home-bound or bed-fast in the municipality is usually bigger than actual number, because of family's' wishes to get financial support from the welfare agency.

The early rehabilitation for stroke patient is key issue to reduce the number of bed-fast patient in Japan. In specific area, local department of health tried to collect the data of whole incidence of stroke by taking the transported cases by ambulance car and report from the emergency department of hospital in Tokyo (ITABASHI-KU). We need to cooperate together among the different services out side of health sector.

A few of the local medical societies challenge to get current information and data on the bed-fast patients in their community. Through this data collection and analysis of the need of community care, medical society proposed to have family physician for each of the bed-fast patient.

In this century, we must find not only scientific but also practical method of the measurement of health and health care for the dementia. Of course, the criteria of clinical diagnosis and psychological assessment push the advancement of this measuring.

At the same time, I would like to stress the importance of the resource allocation for these counseling and assessment. We have to introduce a system for this works by coordinating and integrating the existing resources of health center, hospital and clinic, nursing home and the university or college of medicine and social work. For further effort, we are planning to build a new integrated health and welfare center for the community service and assessment for the need of care of the dementia.

The protection of privacy for the dementia is still now crucial issues in the systematization of data collection.

4. Research and study on the data and information of the health and health care on aging

Major concern in the research or survey on aging focused on the frail elderly to develop long term care in Japan. Recently, some experts of public health reported on several topics regarding to the process of aging and " health care " of the aged. I would like to describe general situation and problems of Japanese research on the health of aging by taking several topics.

1) Health promotion and nutritional assessment of elderly

Very few studies and survey were done on the outcome of sports or recreational activity among elderly for their health. Croquet and dancing are very popular in the community. Tentative research finding shows positive contribution of these activities for reducing the fracture and prevention of dementia, however, still now, there is no well designed randomized control study in Japan. It might be very interesting to develop international comparative study on the effect of sports and recreation for the health of the aged among several countries.

The nutritional assessment and health education for the elderly living alone in the community might contribute effectively to prevent the diseases and injuries. We have very limited information on this topics. But, it is not so difficult research on this topics among countries, if we will design new international study projects.

There is a discussing topics as the controversy relating to animal protein and fat for Japanese elderly. A group of epidemiologists deny the effect of traditional Japanese food of vegetable oil and protein which was considered as a contributor for longevity by gerontologist or community physicians.

2) Longitudinal data on aging

In Japan, because of the lack of effort by the government and academicism, there is no data of longitudinal study in the specific community. So called KOGANEI Study was developed by the epidemiologists of Tokyo Metropolitan Institute of Gerontology by taking a specific age group in the suburb of

Tokyo.

3) Productive aging and the capacity to work

Japan must develop the research on productive aging and capability of working among elderly by looking the need of senior labor in next century. We should push the concern and interest of the leaders of business.

Ministry of Industry and Trade and Ministry of Health and welfare of Japan are tending to become very eager to the economic development of so called " Silver Industry " which means the expansion of goods and services as a market, consumed by the rich elderly including housing and resort building.

They should organize the inter-departmental study group of the capacity of work for the elderly. Governmental agency has a good position for the study on the role of senior labor from the view point of production in the economy. It is very superficial understanding to consider the elderly as a consumer only.

4) Identifying the health and social factors which increase the need of long term care

The study on the risk factors of long term care is very slow and few in Japan. But the economic burden of medical cost of long term care inevitably push the research on this topics. In Japan, traditional payment system to health facilities including nursing home have negative position for the development of this kind of service and research. In other words, there is no economic incentive for the provider of care who wish to prevent and reduce long term care in nursing home and geriatric hospital in Japan. This country should afford great efforts to reduce the average length of stay (39 days in 1984) in general bed of the hospital.

Even though seventy percent of Japanese elderly in the community is living together with their child, the tendency of institutionalization is exploding in the specific area which had been building geriatric hospital and nursing home. We have to limit and reduce the number of bed to avoid unnecessary institutionalization in this area.

In some municipalities or area, we are keeping low utilization rate of institution. The identification of social factors relating to the heavy burden of the care by family member in their own home is quite important in Japan. We can find appropriate field of research on this topics through international cooperation.

THE POTENTIAL FOR EPIDEMIOLOGICAL STUDIES ON AGING IN ISRAEL

Baruch Modan, Epidemiology Israel

Israel is a country of many contrasts and the Israeli society is extremely heterogenous. Its relatively small constituency of 4.5 million people is crowded into a compact size area that encompasses migrants from almost every corner of the globe. Two thousand year old archaeological ruins can be seen within a short distance of ultra modern architectural structures. Similarly, inhabitants of a multitude of extractions - a cross-fertilization of Jews and Arabs, Samaritans and Crusaders - going back for an infinite number of generations - live across the street from African descendants who have just arrived.

The Israeli medical care system follows the patterns of developed countries. Accordingly, the main causes of death are heart disease, cancer and stroke, with the rates of the first and last categories dropping by 30% over the past 20 years. The infant mortality is low, approximately 12 per 1000, only about one fifth of the magnitude that prevailed 40 years ago when the state was established.

Consequently, the aging problem has become one of the major issues of modern Israel. On the basis of the classic definition of 65 years and above, the proportion of elderly has gone up the past 25 years by 100% - from 4.8% in 1960 to 10% today, while the proportion of 75 years old and above tripled from 1.5% to 4%. Concurrently, life expectancy has increased by 4.1 years in males and 5.5 years in females to 73.5 and 77.1 years, respectively.

Paradoxically, the rising of the aging problem is directly related to the improvement of medical care. The rapid decline of infant mortality, the advent of vaccination, the combat of infectious diseases, better nutrition, lesser crowding, better education, and finally the still unexplained riddle of declining heart disease and stroke mortality, have all contributed to the elderly stratum. The cumulative effect of these parameters of influence within a relatively short period of time, coupled with the fast development of modern technology that sustains an increasing number of individuals in their late 70s, 80s and 90s, has led to a sudden discrepancy between available funds and the absolute number of users. Therefore, the better the level of medical care the larger the number of survivors who become dependent on those health measures, and the higher the ensuing expenditure.

Our discussion will relate to four main topics:

a) Socio-demographic outlook
b) Political structure
c) Assessment of needs
d) Policy decisions

Socio-demographic outlook

Several socio-demographic facets of modern Israel's elderly population are worth further study. First among these is the fact that, in contrast with other western societies, the male to female ratio is close to one. Whether this is an outcome of an early women's liberation or a superior survival of men is yet to be determined. A second feature is the changing inter-ethnic ratio. At present, 73% of the elderly are European born, with a considerable proportion of holocaust descendants, who are relatively well educated, and entail a significant proportion of professionals or skilled workers with sound pension programs. Consequently their problems are more medical than social.

But the inter-ethnic ratio is changing rapidly. If current mortality and migration trends continue, the anticipated change in the inter-ethnic ratio will occur in less than 3 decades, and would provide a unique opportunity to study social transition. The Asian and African born group which will match the strength of the Europeans, numberwise, in just over two decades, differs from the Europeans by having a relatively high percentage of illiteracy among women, fewer professionals among men and somewhat labile pension plans. In consequence the problem areas among the aged are expected to shift from medical to social.

If the interaction of social and medical problems is studied well in advance appropriate planning can be applied and part of the "future geriatrics shock" avoided.

Political Structure

The anticipated socio-demographic changes must create an impact on the political scene as well. The rapid increase in the number of elderly voters will eventually result in a larger number of elderly candidates. Thus, some middle aged political candidates who now dye their grey hair in an effort to blend with their younger constituency will start streaking their hair with silver. Much more important, however, will be the impact on the availability and allocation of resources. It may sound too optimistic but programs for the elderly will become a first priority; not so much because politicians will suddenly be born again, but thanks to their wish to satisfy their voters. Thus, unless appropriate assessment is made, the current chaotic situation of redundant expenditure for the middle aged will probably be replaced by redundant geriatric expenditures, including an array of painful short term treatment schedules, for terminal patients.

Again, the heterogenity of the Israeli population provides a unique set-up for the application of scientific methods to the assessment of needs in the new era of geriatrics.

Assessment of Needs

The major potential contribution of epidemiological studies of future needs is the use of models that could enable us to formulate future budgets within the framework of the dynamic changes that are bound to occur in our society.

Application of epidemiological methods to study health care needs is a relatively new approach. For years, large scale treatment and development programs were decided upon by senior clinicians and health officials on the basis of intuition alone. Now, in the era when clinical freedom has ended, needs must be assessed scientifically on a basis of preset priorities to match available resources and prevent total depletion of funds.

Only 20 years ago, 100 percent of Israeli patients who qualified for renal dialysis died within three months of the onset of their end-stage kidney disease because no treatment facilities were available. Today, after needs have been scientifically estimated and a major policy decision made, the dialysis rate in Israel is one of the highest in the world.

Unfortunately this is not always the case. A national center for liver transplantion was established in our country and a heart transplantation unit declared upon, with no idea whatsoever of how many patients would qualify for such services when they become available, and what other patient groups will be deprived of services for which the needs had not been scientifically determined. Hip transplants, a much less glamourous procedure, is an even better example.

Public Policy

Public policy is a product of all the components that have been discussed above. Ultimately it is an outcome of needs, resources and pressures, with an ability to compromise and divert funds to newly arising needs. Again, a wise compromise can be made only on the basis of meticulous data accrual, to estimate needs that would provide an objective assessment for resource allocation.

Health Policy is a budding discipline, and the development of specific models for particular needs of distinct populations is one of its first targets. In the field of epidemiological research on aging, the above statement points to a need for new methodology: shorter questionnaires, simpler questions, interviewers who are sensitive enough to observe when an old person is tired and when his or her answers become blurred, boldfaced printed cards, and more sophisticated techniques to validate proxy interviews when impaired individuals cannot respond directly.

One of the major deficiencies is the lack of specific criteria and scores of measurements. Our current concepts of health and disease may be inappropriate for the elderly, and are definitely unsuitable for the oldest old. Innovative scores that may be derived from the ADL scale, but would be much more comprehensive, are urgently needed and should be developed.

For years our group has struggled in vain with one such potential score summarized by the acronym L'HAIM (meaning "to life" in Hebrew) - that incorporated Life style, Health, Activity, Intelect and Motivation; but we failed to cross bureaucratic barriers that would enable us to assess its validity through a longitudinal study.

The new methodology detailed above may provide some acute answers to questions that have became the focal points of our life since it became a common notion that individuals may, in fact, continue living until they are 120.

WHO Programmes on Chronic Disease Prevention
- experiences of the North Karelia Project in Finland -

Aulikki Nissinen, World Health Organization, Geneva, Switzerland

The North Karelia Project

The North Karelia Project was designed as a response to a petition of representatives of North Karelia, signed in 1971. This petition urged the Finnish Government to take action to reduce the extremely high heart disease rates in the area, and resulted from alarming information on high morbidity and mortality rates in the Finnish population as a whole and in North Karelia in particular. The project was from the very beginning seen as a pilot programme to develop and test methods for nationwide control of cardiovascular diseases and it was formulated and launched in close cooperation with Finnish experts and WHO (Puska et al. 1981).

The major objective of the programme in North Karelia was to decrease mortality and morbidity rates of coronary heart disease (CHD) and related major cardiovascular diseases (CVD) among the whole population in the area, but with special reference to middle-aged men. The main emphasis was on primary prevention through general reduction of the population levels of well-established risk factors: smoking, high serum cholesterol and high blood pressure. A comprehensive educational and service-oriented programme to modify the risk factor profile of the population was based on local community action and local service structure. A central aim was to promote lifestyles that reduce risk factor levels and promote health. Practical skills were taught, social support was provided and environmental modifications arranged as part of the comprehensive community organization for change (Puska et al. 1981, 1985).

For evaluating the programme a quasi-experimental study design was used. At the outset the neighbouring county of Kuopio, matched to North Karelia as to disease and socioeconomic patterns, was chosen as reference area. Risk factor changes in the middle-aged populations were assessed by carefully standardized examinations of large independent cross-sectional random samples in North Karelia and the reference area at the outset in 1972 and at five years intervals. It should be noted that as a national demonstration programme, after the initial five years (i.e. since 1977) the project has been actively involved in national risk factor reduction activities - influencing also the reference area.

Results and experiences

In spring 1982 a large follow-up survey was carried out in North Karelia and the reference area to assess ten-year changes (Puska et al. 1983). The results indicate major changes in North Karelia, and substantial - although statistically significantly smaller - changes in the reference area (Table 1). Due to lack of strictly comparable data it cannot be said how well the changes in the reference area reflect national changes - or whether the project activities have had a special effect also in the reference area, as may well be the case.

Table 1 : Major risk factor changes from 1972 to 1982 among males aged 30-59 in North Karelia (NK)

	Change in NK %	Net change in NK[1] %
Smoking	-34 ***	-28 ***
Fat intake (from butter and milk)	-29 ***	-16 ***
Serum cholesterol	-11 ***	- 3 ***
Systolic BP	- 3 ***	- 3 ***
Risk factor	-15 ***	-12 ***

1) Adjusted for change in the reference area

*** = p<.001 for statistical significance of difference between 1972 and 1982

Disease rate changes are assessed in the North Karelia project by analysing available mortality and morbidity information concerning North Karelia, the reference area (Kuopio) and - as far as possible - the whole country. The respective population sizes are 180 000, 250 000 and 5 000 000.

Analysis of mortality trends has been based on national mortality data since 1969 which was the year when the ICD-8 classification was adopted and which has been used in Finland throughout the period presented here. Thus three preprogramme years are included. Age adjusted rates for men aged 35-64 years are used. The original objective of the project was reduction in CVD - particularly in CHD mortality. Table 2 presents the mean annual percent decline based on linear regression trend analyses. For the decline in CHD mortality the difference was 30% in favour of North Karelia. The reduction and difference compared with the rest of Finland were greatest in the youngest age group. The difference in decline in favour of North Karelia for the period 1974-79 seems to be the greatest (Salonen et al. 1983). In the 1980's the rest of the country seems to be catching up with this decline.

Table 2 : Mean annual regression-based decline in age-adjusted CVD and CHD mortality of men aged 35-65 in North Karelia and all Finland during 1979-82

	Mean annual decrease	
Disease category	North Karelia %	All Finland %
- CVD (397-459)	- 2.9 **	- 2.6
- CHD (410-414)	- 2.9 ***	- 2.0

** = $p<.01$
*** = $p<.001$

Although the initial main objective of the North Karelia project concerned cardiovascular diseases and notably CHD, evaluation of the project has recently included possible cancer changes in North Karelia and other parts of Finland. There are several reservations with regard to the possible effects of the North Karelia project on cancer rates: e.g. the number of cancer cases is smaller than that of CVD cases, and the lag time is probably longer with cancer response compared with CVD changes. Cancer incidence data was obtained from the national cancer register that codes centrally information on all cancer cases in the country. Preliminary analyses have shown that total cancer incidence developed towards the early 1980's more favourably than in the rest of Finland (Puska P, personal communication).

Table 3 shows survey results that indicate improved subjectively assesed health of the North Karelian population as a consequence of the programme.

Table 3 : Percentage of people in the population surveys reporting subjective health as "very good" or "good" (among 30-59 years old population)

	Men		Women	
	NK	Ref. area	NK	Ref. area
1972	32	35	31	34
1977	39	42	41	42
1982	45	45	52	50

Throughout the years, the feasibility of the programme has been good. This has been the case in spite of the fact that - at least in the early years - health service resources were scarce and society norms were rather traditional and thus resistant to change and diffusion of lifestyle innovations. Local health services and local health personnel have cooperated well and have thus formed a firm backbone to the activities. The local population has participated eagerly and various community organizations have over the years in various ways contributed to the aims of the project in the area. Because the project was integrated in the existing health services and broad community participation was a key feature, the overall costs of the programme have been modest. On the other hand obvious savings have occurred, for instance in reduced disability payments (Puska et al. 1981).

Since 1971 there has been active cooperation from WHO, both the Regional Office for Europe in Copenhagen and Headquarters in Geneva, in planning the programme. Later on, the Project took part in several WHO programmes, such as (1) the Community Control of Hypertension (1972-1982), (2) the Comprehensive Cardiovascular Community Control (1974-1982, Puska et al. 1987), (3) the International Monitoring of Trends and Determinants of Cardiovascular Diseases, MONICA Project, (1982 onwards, Tunstall-Pedoe 1985), and (4) the European region and the global Integrated Programme for Community Health in Noncommunicable Diseases (INTERHEALTH), the Countrywide Integrated Noncommunicable Diseases Intervention Programme (CINDI) (1982 onwards).

Research activities among the elderly in North Karelia

Intervention in the North Karelia Project has targeted the whole population. Thus the elderly have been included in the prevention and control activities. For instance, the reorganized hypertension care since 1972 has involved patients of all ages. However, due to scarce resources, evaluation has assessed the effects of the project only among the middle-aged population. Apart from data collected in the community-based hypertension register, which includes some 7000 patients over 65 years (30% of all registered hypertensives), and the stroke register, which includes patients below 75 years, there exists very little other information on the older age groups in North Karelia. Thus relatively little so far is known about trends in health behaviour of the elderly and scarcely anything about the underlying factors. The results of one small-scale survey done in 1982 among 65-74 year olds in North Karelia using the same protocol as a Portuguese study, indicate that those who had been middle-aged ten years earlier and thus the target group of the project, were concerned about their own health (Nissinen et al. 1987).

In 1958, a large international study was started to examine the association of selected risk factors with the development of CHD within different populations (Keys 1980). Between 1958 and 1964, 12763 men aged 40 to 59 years were examined in USA, Italy, the Netherlands, Finland, Greece, Yugoslavia and Japan. The study has accordingly been called the Seven Countries study. The Finnish part of the Seven Countries Study (Karvonen et al. 1967, Keys 1970), called the East-West study was started in 1959 with two cohorts of men born 1900-1919; another consisting of 823 men in the eastern part of Finland (in North Karelia) and another consisting of 888 men in the south-western part of Finland. Baseline data showed a difference in CVD risk factors between eastern and western Finland and the results contributed to the official mortality statistics used as a basis for the initiation of the North Karelia Project.

The two cohorts were re-examined in 1964, 1969, 1974 and in 1984, when the men were 65-84 years old (Nissinen et al. 1986). This 25-year follow-up has enabled a study of secular trends in serum cholesterol, blood pressure, smoking and body mass index in the cohorts between 1959 and 1984. These trends can provide some insight into the reasons why a rapid decrease in CHD mortality has taken place in Finland during the latter part of this period. The study also provides information on possible changes in the difference in mean levels of these risk factors between East and South-west Finland. It has been possible also to examine the association of these risk factors with CHD and death during a long follow-up of middle-aged men with high incidence of CHD.

Longitudinal analysis of the data shows how health behaviour related factors like diet measured by serum cholesterol, systolic blood pressure, smoking and body weight in middle age, predict a probability of coronary heart disease in later life (Table 4) (Pekkanen 1987). The results from the 25-year follow-up show an exceptionally high level of diabetes mellitus among these cohorts (Tuomilehto et al. 1986).

The 25-year follow-up survey has also been realized with the cohorts of the Seven Countries study in the Netherlands by Professor Kromhout (the results have not yet been published) and in Italy (The Italian Research Group 1986).

Table 4 : Estimated probability of CHD death and hard CVD event 1959-1984 for a CHD-free man aged 50 living in east Finland by a given risk factor level in 1959

Chol[1]	BMI[2]	Syst BP[3]	Smoking[4]	Risk in 1959-84 CHD death %
-	-	-	-	14.3
+	-	-	-	19.4
-	+	-	-	20.2
-	-	+	-	26.3
-	-	-	+	26.4
+	+	-	-	27.0
+	-	+	-	34.6
+	-	-	+	34.7
-	+	+	-	36.0
-	+	-	+	36.1
-	-	+	+	45.4
+	+	+	-	46.3
+	+	-	+	46.4
+	-	+	+	56.9
-	+	+	+	58.7
+	+	+	+	70.8

1) Serum cholesterol in 1959 - = 5.79 mmol/l
+ = 5.80 mmol/l
2) Body mass index CHD death - = -21.5 kg/m^2
+ = 25.6 kg/m^2
3) Systolic blood pressure in 1959 - = -155 mmHg
+ = 156 mmHg

4) Smoking in 1959 - = -9 cig/day
+ = 10 cig/day.

Conclusions

The Finnish experience and results so far support the idea that a well-conceived comprehensive community-based programme can have a positive impact on lifestyles and cardiovascular risk factors in a whole population, and that such a development is associated with reduced cardiovascular mortality rates. Lifestyle changes are likely to influence favourable also other chronic diseases and promote health in general. The experiences also demonstrate the potential of a community-based approach for changing the risk factors as well as providing practical experience in organizing such activities within health services and other community settings both in developed and developing countries.

The target of intervention in the North Karelia Project like in other community control programmes of cardiovascular disease, has been the whole population. However, the older age groups as well as the younger segments of the society have not been included in the evaluation of the programme. This has mainly been due to lack of resources. The WHO MONICA project gives the possibility to assess lifestyle and biological risk factors and their consequences measured by cardiovascular diseases also among older age groups with relatively low additional resources.

Continuation of morbidity follow-up of active long-term cohorts as in the Seven Countries Study, with the inclusion of repeat risk factor level examinations, morbidity measurements and assessment of mental and functional capacities, would provide valuable information on the impact of lifestyle at various ages on later life.

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WHO INTEGRATED PROGRAMME FOR COMMUNITY HEALTH IN NONCOMMUNICABLE DISEASES (INTERHEALTH)

E.N. Shigan, World Health Organization, Geneva

INTRODUCTION

The idea of the Integrated Programme for Community Health in Noncommunicable Diseases was born in 1978 in connection with the Alma-Ata Conference on Primary Health Care and the development of the conceptual framework for Health for All by the Year 2000 (HFA 2000).

The WHO Steering Group (1983) formulated a definition of an integrated programme as follows:

> An integrated programme for the prevention and control of noncommunicable diseases combines, in an operationally feasible manner, resources and approaches currently being devoted to the prevention and control of selected noncommunicable diseases and related conditions, and it permits the managerial unification of a set of preventive and other control activities that should lead to the prevention and control of major noncommunicable diseases and to the promotion of health in total communities.

A key concept supporting the rationale for integration is recognition that achieving control of a small set of risk factors and improving the interaction among a small set of health and other services may have a major impact upon a much larger set of disease conditions. This magnification of impact holds the potential for achieving more effective and greater improvement in the health of populations at less economic cost than addressing each disease entity separately.

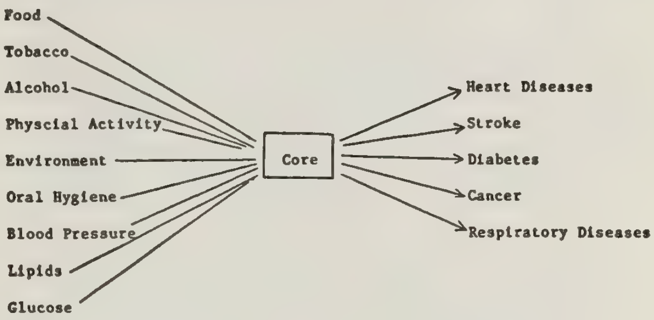
Since then a number of meetings at the global and regional levels have taken place to discuss various aspects of the problem and programme concepts have gradually crystallized:

- prevention and control of common risk factors for a group of noncommunicable diseases;
- total community involvement including all age/sex groups of population;
- integration of different health promotion intervention strategies (population strategy, high-risk strategy, screening for early diseases detection, primary, secondary and tertiary prevention);
- implementation of prevention and control activities through existing PHC and other public health and other community structures;
- intersectoral collaboration;
- integration of different categories of intervention (legislative action, health services and individual behaviour change);
- monitoring and evaluation of the programme and its individual components.

Development of INTERHEALTH was stimulated to a greater degree after the adoption of resolution WHA38.30 (World Health Assembly 38.30) in 1985.

METHODOLOGY

Programme Content - Fig. 1



As seen from Figure 1, all these diseases are chronic and are the sad 'privilege' of old-age.

Programme Structure

Programme - set of partial subprogrammes oriented to:

(a) change in behaviour of individuals and populations in everyday life and especially in connection with the above-mentioned risk factors;

(b) building public health policy;

(c) reorientation/reorganization of the health service;

(d) reorientation/reorganization of other sectors, activities, etc.

Programme Procedure

This procedure includes the following steps:

(a) identification of NCD problems;

(b) situation analysis (baseline information);

(c) formulation of aims and objectives;

(d) elaboration of a set of intervention programmes;

(e) intervention;

(f) monitoring and evaluation;

(g) implementation of the results.

Flexibility of Interhealth Methodology

The universal INTERHEALTH methodology

developed in WHO/HQ should be adapted to the situation of the WHO regions, their environments, lifestyle, and so on. It means that there could be some modifications, but the main skeleton should be the same. INTERHEALTH should, in Africa, be linked with infection and family planning programmes, and in Europe and North America with programmes for the elderly, etc. It means that WHO/HQ methodology should be flexible and give, on the one hand, opportunities to include (or exclude) some factors or diseases, and on the other hand enable linkage with other ongoing programmes. At the country level the process of adaptation will be related to specifics of the health care systems, health legislation, existing infrastructure. For some large countries, like USA, China, India, Canada, USSR, and others, where there are a lot of differences from one part of the country to another, some additional components related to district or community specific should be taken into account.

In order to develop INTERHEALTH methodology we are cooperating with WHO regional offices, some divisions within WHO/HQ, and also with some international and national research centres dealing with epidemiology and statistics, social medicine, public health and health care management.

DEMONSTRATION PROJECTS - the main source of information

Taking into account regional, social, demographical, geographical, cultural and other differences among WHO regions and countries, as well as the lack of sufficient intervention about the effectiveness of integrated NCD programmes, WHO/HQ promoted the establishment of a series of demonstration projects in all WHO regions, the objectives of which were as follows:

- to test, apply and estimate the efficiency and effectiveness of the INTERHEALTH intervention programme from the medical, economic and social points of view before extending the INTERHEALTH activity to the whole country or region;
- to use the results of the project experiment for the demonstration and training of national and international staff;
- to use the demonstration project data for developing a family of scenarios and mathematical models for testing and evaluating different intervention alternatives and combinations.

Eighteen demonstration projects were established or are in the process of development in fifteen countries in all WHO regions. The demonstration projects consist of experimental communities and reference communities.

Types of Data

The following data should be collected:

(a) sociodemographic;

(b) mortality rates;

(c) morbidity: e.g., incidence and prevalence rates, trends, distribution in populations, causes;

(d) disability associated with NCD;

(e) personal habits;

(f) risk factors associated with NCD;

(g) health education of the public: assessment of actual and potential capacity in NCD control, evaluation of impact;

(h) medical-care facilities: assessments of capacity, performance, and potential;

(i) medical-care utilization measurements;

(j) costs;

(k) evaluation of intervention programmes.

Sources of Data

I. Information from communities:

   (a) data routinely available - such as those from registration systems for mortality and demographic data, health service systems, community-based registries, censuses;

   (b) data that can be obtained from review of existing primary information such as that derived from hospital records, or consumption data, e.g., cigarette sales.

II. Information from individuals:

   (a) data derived from questionnaires:

      (i) postal surveys;
      (ii) interviews.

   (b) data derived from physical examinations or laboratory tests.

III. Information about medical staff opinion.

Time Points for Data Collection

Data are collected for baseline evaluation purposes just before a programme begins, and at one or more monitoring points during or at the end of the programme. Both sources of data are likely to be needed: viz, the community and individuals etc. A core set of information should be collected at baseline from all sources. This core set, which could be common to all communities, will need to be supplemented by other information, depending on the programme and the particular community. Also, the baseline information collection could be repeated or supplemented at the monitoring points.

Utilization of Demonstration Project Results

I. Extension to the whole country or region

The results of the demonstration project, after evaluation from the medical, economic and socio-behavioural points of view, could be estimated on the basis of national intervention programmes, legislation, administrative and other decisions if positive. Even the negative results of some intervention programmes will be quite useful for the decision-maker and will assist him in developing new approaches and alternatives.

II. Demonstration and training

The result of the demonstration project, its programme design, supporting systems, etc., will be useful for:

- other INTERHEALTH demonstration projects;
- decision-makers, medical staff, primary health workers from other communities, districts in the same country;
- representatives of other countries.

A special training course or seminar should be organized on the basis of demonstration project experience, perhaps similar to that of the North Karelia demonstration, visiting programme in Stanford, etc. Beginning in 1988, special training courses will be conducted in the USSR (Moscow, Kaunas and Riga) on a regular basis. All training programmes and modules will be available to all WHO regions.

III. Mathematical modelling

The result of a demonstration project could be used in developing different mathematical models for testing and forecasting alternative strategies.

FUTURE DEVELOPMENT

Further programme development requires reorientation of the priorities in specific approaches. More attention should be paid to the health promotion programmes, which should be specified in relation to life span transition (antenatal, infancy, childhood, adolescence, and so on) and special population groups (schoolchildren, women, workers, elderly).

For developing this task we are going to cooperate with the WHO Regional office for Europe, who have some good results in programme health promotion problems, and in the programme for the elderly. We are planning to establish several Collaborating Centres for the development of health promotion components in INTERHEALTH. Particularly for the development of the "health for the elderly" component in INTERHEALTH we have agreements with the National Institute for Aging (USA) and the Institute of Gerontology (USSR).

Taking into consideration available data and new evidence about risk factors and noncommunicable diseases it is necessary to extend, specify and to design the set of anti-factor and anti-disease INTERHEALTH programmes. We are going to develop smoking and diet components to increase environmental impact in INTERHEALTH. Much more attention should be paid to psychosocial factors and their relationship with many noncommunicable diseases, and to implementation of the anti-stroke programme to INTERHEALTH.

All these additional components of INTERHEALTH will be tested on some existing demonstration projects.

By using the data of demonstration projects, collaborating centres, and risk assessment methodology we are going to develop a set of simulative models for testing different scenarios related to the specific situation in different regions and countries, their principles of health care systems, public health infrastructure, socio-economic and other conditions.

It will give the opportunity to decision-makers of national ministries of health (or similar authorities):

- to use results of the nearest demonstration project as an example for developing their own programmes;
- to put into a universal simulative model their own national statistical and epidemiological data and test some scenarios in developing their national INTERHEALTH programme.

In order to join all these components into one system and increase the quantitative aspects of INTERHEALTH we intend to establish close contact with IIASA (the International Institute for Applied Systems Analysis, Laxenburg, Austria), MEDIS (Institut für medizinische Informatik und System Forschung, Munich, FRG), and with Duke University, Durham, North Carolina, USA.

Up to 1989 a manual will be developed for INTERHEALTH methodology and modules for specific programme components, standardized information received on the baseline situation in all demonstration projects, and a family of simulative models for testing different scenarios related to different conditions prevailing in countries and regions, as well as a set of education and training programmes for INTERHEALTH development and implementation will be elaborated.

Future development of INTERHEALTH within the WHO Eighth General Programme of Work (covering the period 1990-1995) will be dedicated to the intensification of epidemiological and health care components and the development of separate manuals (with education, training programmes and models) for specific groups of the population - children, teenagers, adults, elderly, women, etc.

PANEL ON INTERNATIONAL ACTIVITIES IN DATA AND RESEARCH ON AGING

Other Panelist:

A. Michael Davies, M.D.
School of Public Health and Community Medicine, Jerusalem

(Not available for publication)

Session K

Hospital-Associated Health Care

DATA FOR AN AGING POPULATION

TRENDS IN HOSPITAL SERVICES FOR THE AGED

Ross M. Mullner, University of Illinois at Chicago
William A. Read and Peter D. Kralovec, American Hospital Association

Introduction

Hospitals have long played a pivotal role in providing health care services to the aged. No other health care institution serves the elderly more than the community hospital. In 1986, for example, more than four million -- 20% -- of people 65 years of age or older in the U.S. used hospital inpatient facilities at least once during the year accounting for 10.8 million admissions.

With the aging of the nation's population and recent changes in the financing of health care for the elderly, hospitals are changing the number and type of services they offer. To identify these changes, the results of two national surveys conducted by the American Hospital Association (AHA) are of particular importance.

The objective of this paper is twofold. First, it will describe the two surveys: the National Hospital Panel Survey, and the Survey of Hospital Services for the Aged and Chronically Ill. Second, it will discuss some of their major findings concerning the elderly and the services they receive.

National Hospital Panel Survey

The National Hospital Panel Survey is the only source of monthly data about the finances and utilization of U.S. community hospitals. Conducted since 1963, the main purpose of the survey is to obtain a limited set of data on a monthly basis from a representative sample of community hospitals.throughout the country. From these data estimates of hospital performance, indicators are derived for a series of hospital bed-size groups at national and regional levels.

The questionnaire which asks for information from the previous month is sent to a national sample of 2,000 hospitals. Approximately 1,700 (70%) of them respond to the survey in any given month.

The survey's one-page questionnaire is divided into the following sections:

1. Beds and Bassinets. Includes questions about the number of adult and pediatric beds and the number of newborn beds set up and staffed for use.

2. Utilization. Includes questions about the number of admissions and inpatient days for adult and pediatric inpatients, the number of births and newborn days, the number of outpatient visits by type, and the total number of surgical operations.

3. Finances. Includes questions about revenue, expenses, current assets, and current liabilities.

4. Personnel. Includes questions about the number of full- and part-time regularly employed personnel.

5. Utilization: Age 65 and Over. Includes questions about the number of admissions and inpatient days for elderly patients.

From the 39 data items gathered by the questionnaire, estimates are made of more than 100 hospital indicators. These include:

Beds. Staffed beds; staffed bassinets.

Finances. Total expenses; expenses per adjusted patient day; expenses per adjusted admission; labor expenses; payroll expenses per full-time equivalent (FTE) employee; non-labor expenses; interest expenses; depreciation expenses; supply expenses.

Personnel. FTE personnel; staffing ratio (FTE per patient day).

Utilization. Total admissions; 65 and over admissions; under 65 admissions; surgeries; 65 and over length of stay; under 65 length of stay; patient census; outpatient visits; occupancy rate.

Data reported on each hospital's survey are checked by computer edit for internal consistency with data reported on earlier surveys, or for consistency with responses given on the Association's Annual Survey of Hospitals. Hospitals are contacted for clarification and confirmation of responses that fail the edit.

Estimates of these indicators for the universe of community hospitals are made using the hospital bed as the basic unit of computation, since the number of hospital beds is the variable most highly correlated with the other indicators. Each month, indicators are estimated separately for 72 strata reflecting eight hospital bed-size groups (6-24, 25-49, 50-99, 100-199, 200-299, 300-399, 400-499, and 500 or more beds) within each of the nine U.S. Census Divisions. These indicators are then summed over the appropriate strata to produce national and regional indicators for the eight bed-size groups.

Data from the Panel Surveys are available in a variety of forms. Data pertaining to individual hospitals, however, are considered confidential and are not released. The data from each month's survey are processed within 30 days of the end of the reporting period, and the results are published within 75 days. A regular subscription series of Panel reports is available from the AHA's Hospital Information Services. The reports contain national, regional, and bed-size group estimates for 76 performance indicators, and compare current month, year-to-date, and quarterly figures to figures for the corresponding periods of the previous year.

Data are also available in magnetic tape format. Two types of tapes are normally available: monthly national estimates for all Panel indicators classified by eight bed-size groups which cover 1963 to the present; and monthly regional (nine U.S. Census Divisions) estimates of the same data for the same time period.

Figures 1 - 3 show some of the major findings from recent analyses of the Panel Survey. Specifically, Figure 1 shows the total number of inpatient admissions to community hospitals for those 65 years of age and older and those less than 65 for the twenty year period 1967-86. The figure shows that overall the number and proportion of hospital inpatients who are elderly has increased greatly. In 1967, for example, 5.3 million admissions or approximately 20% of all admissions were for those 65 years or older. By 1986, the number had increased to 10.8 million accounting for 31% of all admissions.

Figure 1 also shows that the number of elderly inpatient admissions grew steadily each year until it peaked in 1982 at 11.8 million admissions. After that year it declined slightly each year. The reason for this decline in admissions most likely reflects changes in Medicare's prospective payment system.

Using the same data, Figure 2 presents a seasonal (monthly) index of hospital admissions averaged over the same 20 year period. These data were adjusted to control for variations in the number of days per month. If an equal number of admissions occurred every month over the years the index would be 1.00 for each month. Since 1.00 represents the monthly average over the years, any larger value represents a greater than average number of admissions. Similarly, any lesser value represents a lower than average number of admissions.

Figure 2 clearly shows the elderly have a different seasonal pattern of admissions than the non-elderly. While both groups have a similar index in January, the index for the elderly tends to decline and reach a low point (.96) in August, increase to October (1.00) and decline in December (.96). In contrast, the index for the non-elderly tends to decline and reach a low point in May (.98), increase slightly in June (1.02), and decline greatly in December (.91). These patterns may indicate that the elderly have different health care needs and are responding differently to temperature and weather conditions.

Figure 3 shows the average length of stay for those 65 and older and those less than 65 for the twenty year period 1967-86. Overall, the average length of stay for the elderly decreased greatly during the period. After peaking in 1968 at 13.36 days, their average length of stay declined each year to 8.79 days in 1986. In contrast, the average length of stay for those less than 65 also declined but less dramatically. In 1967, for example, their average length of stay was 6.76 days and by 1986 it was 5.56 days.

Survey of Hospital Services for the Aged and Chronically Ill

To obtain more detailed information on the provision of hospital services to meet the health care needs of the elderly and the special needs of the chronically ill of all ages, a special one time survey (Survey of Hospital Services for the Aged and Chronically Ill) was conducted by AHA. Specifically, the survey was designed to assess the status of long-term care and geriatric services, compile baseline data for trend examinations and facilitate communication among health care professionals about existing and emerging hospital services.

The survey, which was conducted between June 1985 and January 1986 by the Association's Section for Aging and Long-Term Care Services and the Hospital Data Center, was mailed to all (community and non-community) hospitals in the U.S.

The survey instrument consisted of fifteen pages of questions addressing six areas: long-term care services, specific hospital services for the elderly, organizational issues, personnel, education, and the future plans of the hospital.

Data from community hospitals only are presented in this paper. A total of 3,529 -- 59.7% -- of all U.S. community hospitals responded to the survey.

Findings from the survey are contained in a report entitled "Emerging Trends in Aging & Long-Term Care Services" which is part of the Hospital Survey Series published by the Association's Hospital Research and Educational Trust. More information about the data in the survey can also be obtained from AHA's Hospital Information Services.

Results from the survey indicate that 85% of community hospitals provide some type of long-term care services. Specifically, 19.0% own and operate skilled nursing facilities; 14.2% swing beds; 12.3% intermediate care; 3.6% freestanding skilled nursing facility; and 1.4% psychiatric long-term care.

In terms of recent trends in the growth of long-term care services, the survey identified that the number of hospitals owning skilled nursing facilities, and home care increased greatly between 1983 and 1985. Specifically, the number of hospitals which owned and operated home care more than doubled; skilled nursing grew by nearly 50%.

FIGURE 1: U.S. COMMUNITY HOSPITAL STATISTICS
NUMBER OF ADMISSIONS
1967 - 1986

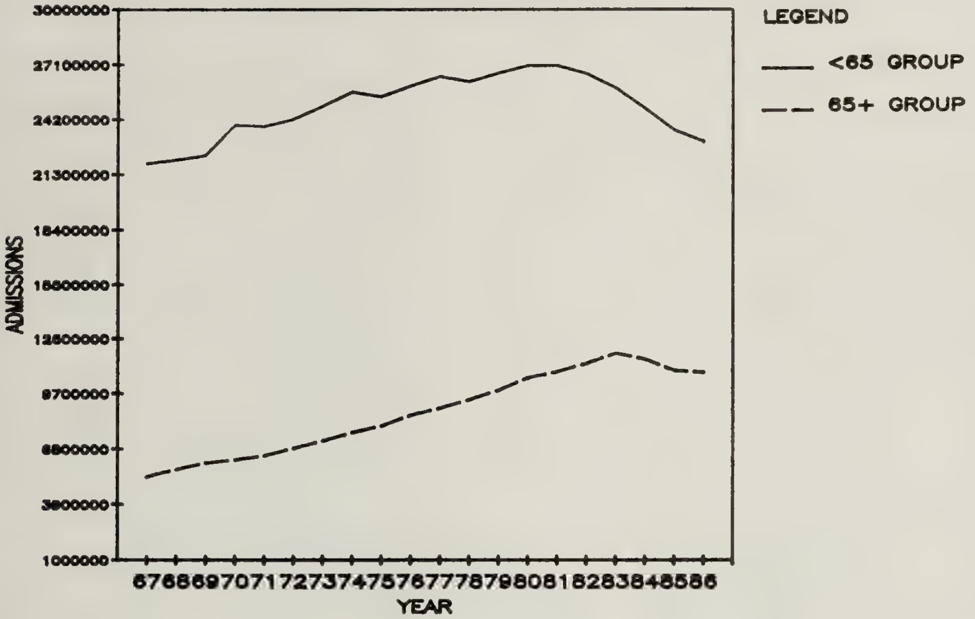


FIGURE 2: U.S. COMMUNITY HOSPITAL STATISTICS
DAILY ADJUSTED ADMISSIONS
AVERAGE FOR 1967 - 1986

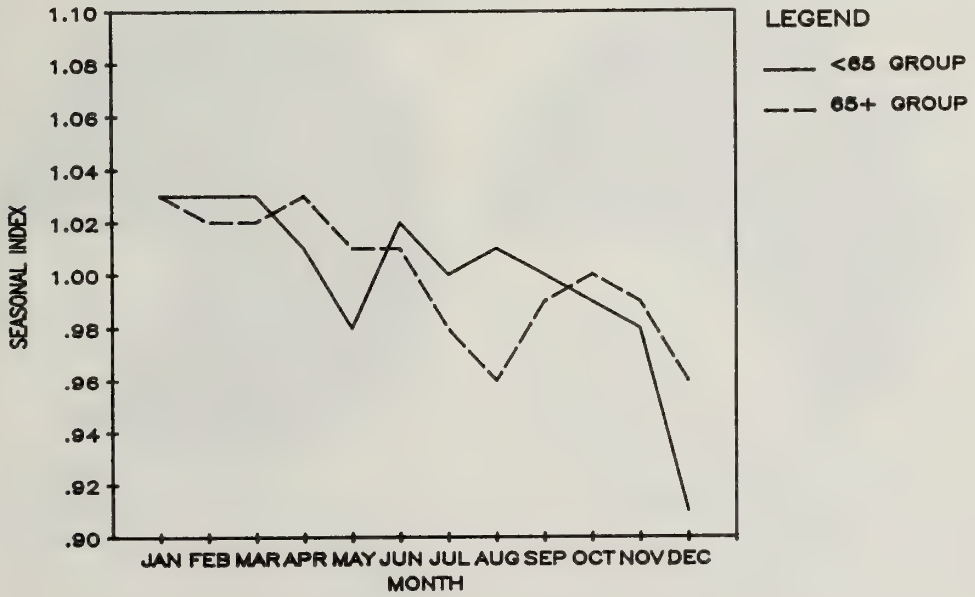


FIGURE 3: U.S. COMMUNITY HOSPITAL STATISTICS
AVERAGE LENGTH OF STAY
1967 - 1986

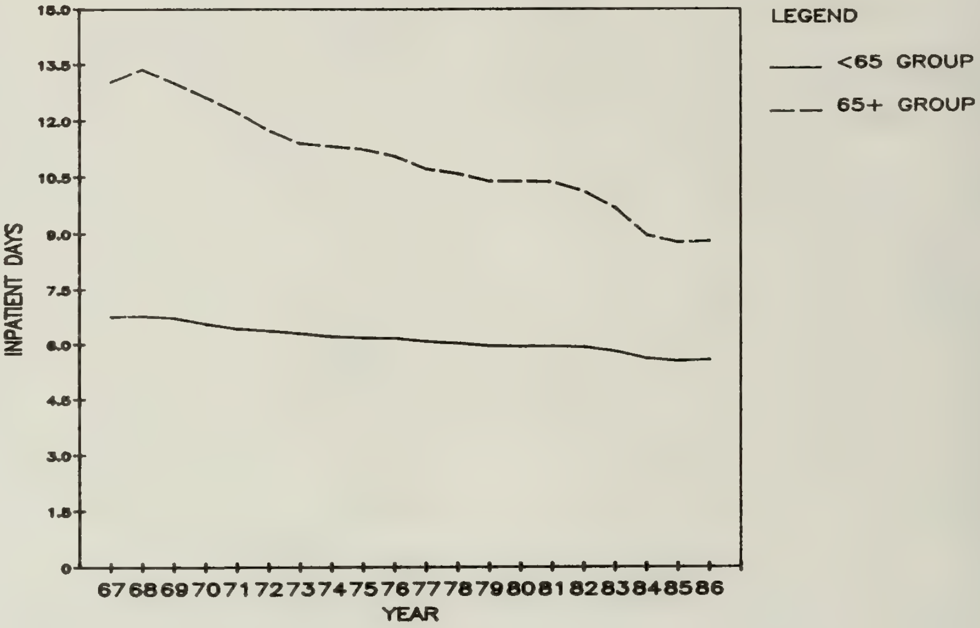
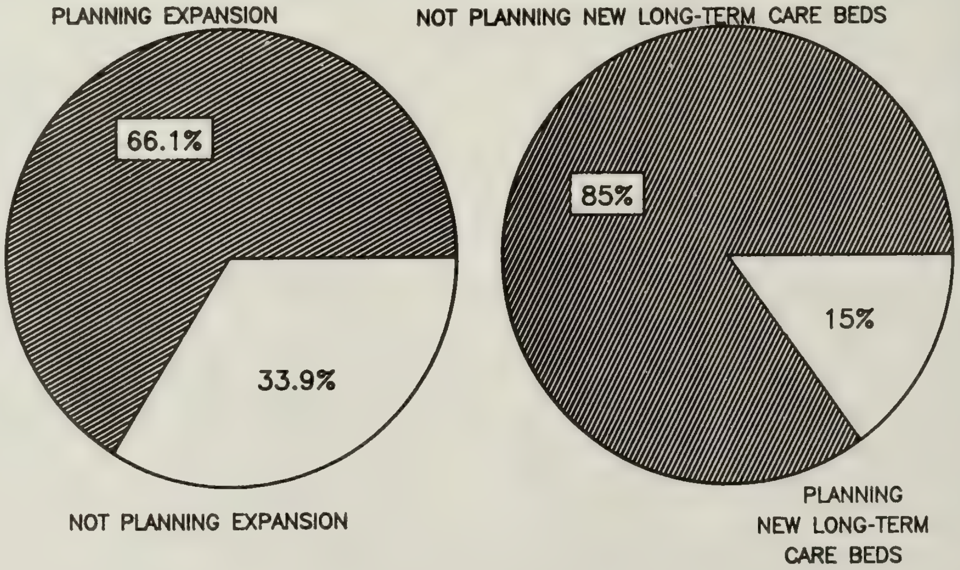


FIGURE 4: PLANNED NEW SERVICES FOR THE ELDERLY
U.S. COMMUNITY HOSPITALS, 1985 - 1986



The survey also identified some of the least available long-term care services. For example, only 2.3% of the reporting hospitals owned and operated senior apartments. Comprehensive care retirement centers and sheltered housing were each only available in 0.8% of hospitals. Foster care services were offered by only 0.4% of the hospitals.

To measure recent changes in the organization and delivery of services to the elderly, the survey asked hospitals about significant changes they experienced since October of 1983. Since that time, hospitals reported they have increased their emphasis on discharge planning (80.7%), implemented new programs and services to address a wider range of health needs (59.4%), installed a new information system for DRGs or cost accounting (55.8%), and increased the coordination of already existing services (54.5%).

Hospitals were also asked about their future plans to develop or expand their services for the elderly. As shown in Figure 4, a total of 66.1% of the hospitals reported that their long-range plans include development or expansion of services for the elderly. In terms of beds, 15% indicated they plan to establish new long-term care beds. Of these, 60.9% plan to convert acute care beds, 29.4% are establishing new beds, and 7% plan to do both.

Conclusion

These two surveys provide researchers and policy analysts a rich source of data and information about the elderly, the services they receive, and how hospitals are responding to a changing health care environment. They also provide a basis for making projections about the future health care needs of the elderly.

PILOT STUDY TO MEASURE THE ADEQUACY OF POST-HOSPITAL CARE

Marian Gornick, Mary Harahan, Larry Kucken, Barbara Phillips, George Greenberg, Paul Eggers, Floyd Brown, and Robert Clark

INTRODUCTION

It has been widely reported that in October 1983 the Medicare program altered its methods for paying hospitals. The new hospital prospective payment system— known as PPS—brought to an end the former cost-based reimbursement system, which had been in effect since Medicare began in 1966 and instituted in its place a payment system with prospectively set rates based on diagnosis related groups, commonly known as DRGs.

In its very first year, the change from retrospective cost-based reimbursement principles for hospital payment to a prospective payment system had striking effects. With regard to Medicare beneficiaries, although the average length of stay was expected to fall, the actual decrease experienced was more pronounced than was projected. And, contrary to nearly universal expectations, admission rates fell.

From the very beginning of the new payment system the Health Care Financing Administration (HCFA) designed a broad program of studies to evaluate the impact of PPS on providers of care, on the health care industry, on the Federal government, and on the Medicare beneficiaries. Because the new system was intended to provide an economic incentive to restrain resource use and to maximize efficiency, the immediate concerns were to evaluate any unintended effects on Medicare benificiaries with regard to (1) curtailing access to care or (2) lowering the quality of hospital care.

Early studies following the introduction of PPS and conducted either intra-murally or through HCFA's grants and contracts program, were designed to focus on these two issues. To determine if PPS had curtailed access to hospital inpatient care for certain vulnerable sub-groups of the Medicare population such as the oldest of the elderly, or minority persons, or the disabled, studies were undertaken to look at changes in admission rates and length of stay for these sub-groups compared to other Medicare beneficiaries. To determine if PPS had lowered the quality of care provided in the hospital, studies were begun to examine changes in the process of care and in the outcomes of hospital care, as measured by changes in the care provided in the hospital and by changes in mortality rates and readmission rates. In all, twelve major quality of care studies were begun.

Sicker and Quicker Issue

None of these studies, however, addressed the very pressing questions raised by the Congress and others about the impact of discharging Medicare patients when they were sicker than they were before PPS went into effect. There were a number of concerns surrounding this issue, including questions about the availability of post-hospital care in the community, questions about the barriers to receiving that care, and the risk of adverse outcomes from inappropriate post-hospital care.

The discussion that follows provides an overview of the the design and development of a study currently underway to assess the appropriateness of Aftercare services.

First, the study would have to consider the types of services beneficiaries need and use after being discharged from the hospital, which can range from skilled nursing facility care to personal care services needed to carry on the activities of daily life. However, information about many of the services the aged use after discharge are not in HCFA's administrative records, because Medicare covers only skilled nursing and home health agency services.

A second data issue to be considered in conducting an Aftercare study is the need for information on adverse outcomes. Although data on mortality and readmissions are available in HCFA records, information is not available on falls and other adverse events, unless Medicare covered services are used.

It became evident that the only way to answer these "Aftercare" questions would be to track patients from the hospital into the community to collect data about the use of post-hospital services.

Additionally, methods would be needed to identify patients who were most likely to need Aftercare services and who might be most likely to have an adverse outcome.

Another consideration was whether or not it would be possible to define a set of agreed upon post-hospital services that particular types of patients would need.

Discussions with discharge planners revealed that although discharge planning has been an activity undertaken for a long time, discharge planners do not generally keep in contact with patients discharged to the community to see if the services prescribed are actually received and if they meet the needs of the patients.

DEVELOPMENT OF AN AFTERCARE STUDY

In thinking about the objectives of the national Aftercare study it was concluded that not only would it be desirable to evaluate the appropriateness and effectiveness of post-hospital services for Medicare beneficiaries discharged to the community but it would be important as well to determine the nature and extent of the problems encountered by patients in obtaining post-hospital care. That is, the study objectives would include identifying barriers to the receipt of needed services, the burden on informal caregivers, out-of-pocket costs, and patient satisfaction.

Because the issues surrounding the study are those that cut across the responsibilities of both HCFA and The Office of The Assistant Secretary for Planning and Evaluation (ASPE), HCFA and ASPE decided to jointly direct and fund a national Aftercare Study.

Having determined that no overall approach for a national Aftercare study was available in the literature, we decided that it would be cost-effective to conduct a pilot study first to develop and test approaches for the national Aftercare study.

Contractual arrangements were made with Systems Sciences Incorporated and their subcontractor, Mathematica Policy Research.

The pilot study began in the Spring of 1986. The two major objectives of the pilot study are shown in Figure 1. At this time, the development of methods and data collection strategies are nearly completed.

Figure 1

PILOT STUDY OBJECTIVES

1. **To develop methods and data collection strategies for the National Study.**
2. **To field test and refine study approaches.**

Target Population

The pilot study target population consists of elderly Medicare beneficiaries discharged to the community from acute care hospitals. The study sample will be drawn from two States representing short and long length of stay patterns. The States chosen for the pilot study are Ohio and Washington. A total of eight hospitals will be included in the sample representing urban and rural areas evenly divided between the two States. Approximately 1,300 patients will be included in the pilot study.

Each of the study methods and data collection strategies being developed in the pilot study is described, in turn, next.

Patient Screening

Patient screening will be utilized in this project to define the study population and to selectively sample patients who are at relatively higher risks of experiencing inappropriate Aftercare and experiencing adverse outcomes. Two types of screens are used: a study population screen and a risk classification screen.

The purpose of the study population screen is to identify patients who are at risk of needing some type of aftercare. This represents the initial screen for identifying patients to be included in the study. As shown in Figure 2, patients are will be screened into the study population based upon diagnoses and surgical procedures generally believed to be associated with Aftercare needs. Patients will also be screened into the study if their functional status. or ability to performactivities of daily living (ADL), indicates a need for Aftercare --without regard to their diagnosis or the surgical procedures performed during their hospital stay.

Figure 2

STUDY POPULATION SCREEN

- o **Based on:**
  - — **Diagnoses**
  - — **Surgical procedures**
  - — **Functional status**
- o **Associated with need for:**
  - — **Post-hospital nursing care**
  - — **Therapy**
  - — **Personal care**

Diagnostic and surgical procedure data will be abstracted from the medical record within 2 weeks following discharge. Functional status data will be collected during the screening portion of a patient/caregiver telephone interview 2 weeks following the patient's discharge from the hospital.

Having first identified a study population based upon diagnoses, surgeries, and functional status, a risk classification screen will be used next to categorize patients based upon their relative risks of experiencing inappropriate Aftercare and experiencing adverse outcomes. This second patient screen provides the basis for insuring statistical precision. Patients at high risk of experiencing insufficient care, resulting in adverse outcomes are likely to be relatively rare. Thus, there is a need for an adequate sample of high risk patients.

As shown in Figure 3, the approach used for classifying high-risk patients is based on a number of data elements gathered during the 2-week post discharge interview and the patient's medical record. These include data on severity of illness, social/living arrangements, functional status, and other patient characteristics.

Figure 3

RISK CLASSIFICATION SCREEN

- o **Based on:**
  - — **Availability of family caregiving**
  - — **Receipt of discharge planning**
  - — **Availability of formal services**
  - — **Severity of illness**
  - — **Functional status**

Guidelines on Post-Discharge Care

Another major component of this study will be the use of guidelines of care, developed by a consensus panel. The Aftercare guidelines have been developed by a panel of clinicians including physicians, nurses, social workers, and physical therapists. These guidelines define minimum amounts of post-hospital services considered to be required based upon a patient's medical condition and functioning. The guidelines consist of the number and timing of post-hospital professional visits and other services needed.

The basic purpose of the Aftercare guidelines is to determine whether post-discharge services received by elderly Medicare beneficiaries are appropriate by comparing services received with these minimum professional guidelines of care. The guidelines will be applied to all patients who pass the study population screen and who are selected for the sample.

The Aftercare guidelines represent minimal standards of Aftercare services typically required by specified types of patients They have been designed to represent a threshold which if not met would place most patients at a high risk of adverse outcomes. For example, for diabetic patients who are newly diagnosed and who are insulin dependent, and discharged to the community, the guidelines specify the need for medication monitoring diabetic teaching and other types of minimal care. Each guideline specifies the type of patient, type of care required, the timing and frequency of professional provider visits, and related adverse outcomes associated with sub-minimal care.

Distinct guidelines covering both skilled and unskilled needs have been developed for specific conditions They have been designed to be comprehensive and cover all elderly Medicare patients discharged to a community setting in need of post-hospital services. Figure 4 shows the scope of these guidelines.

Figure 4

SCOPE OF GUIDELINES

- **Cover 2-week period following discharge**
- **Guidelines cover nursing, therapy, and personal care**
- **All common diagnoses and types of care considered**
- **Over 40 guidelines for medical conditions have been defined**
- **Multiple guidelines can be applied to a single patient**

The final component of the study entails patient/caregiver interviews. Patients will be interviewed 2 weeks after discharge to gather information on the use of post-hospital services. Outcome information will also be collected at the 2-week interview and 6 weeks later.

The purpose of the outcome will be to determine the effectiveness of services received and to assess the validity of the patient screens and the aftercare guidelines.

Refinement of Approaches

At the end of the pilot study, methods will be refined by case-by-case clinical record review of full hosptial records and interview data. Outcomes for those whosecare was sufficient according to the guidelines will be compared to outcomes for those whose care was considered insufficient to determine the effectiveness of the guideline approach.

Summary

In summary, this Aftercare study represents a major long-term undertaking in assessing the appropriateness and effectiveness of Aftercare services for the elderly. As shown in Figure 5, it relies heavily on primary data collection in the form of patient and caregiver interviews and is based upon some innovative methods as represented by the patient screening protocol and by the Aftercare guidelines. The use of interviews allows for the collection of some fundamental information on services received, such as informal services and a wide variety of outcome and other data (e.g., provider burden) not otherwise available through secondary sources. The results of the national study will provide comprehensive data on the adequacy of post-hospital Aftercare for Medicare beneficiaries.

A final note: As observed earlier, the impetus for this Aftercare study was the introduction of the Medicare prospective payment system for hospitals. However, it seems clear that many problems relating to the availability and use of Aftercare services by the elderly population existed long before PPS went into effect.

The importance of developing methods to assess the adequacy of Aftercare services will likely increase, as the eldery population continues to grow. That is, as the number of elderly persons grows, the number living alone is likely to grow also, and more will be at-risk to encountering the problems inherent in obtaining appropriate Aftercare services. It is hoped that this study sponsored by HCFA and ASPE will provide useful methods for identifying the problems in the Nation surrounding the Aftercare issues. Very likely other Aftercare studies will also be needed, especially those assessing State and local area issues.

Figure 5

SOURCE OF DATA

PILOT STUDY COMPONENT	HOSPITAL DISCHARGE RECORD	FULL HOSPITAL RECORD	TWO-WEEK PATIENT CAREGIVER INTERVIEW	SIX-WEEK PATIENT INTERVIEW
SCREENING	X		X	
RISK CLASSIFICATION	X		X	
GUIDELINES				
MEDICAL CONDITION	X	X		
OTHER PATIENT/CARE-GIVER CHARACTERISTICS		X		
ACTUAL SERVICE RECEIPT			X	
OUTCOMES*			X	X
PROBLEMS IN OBTAINING CARE			X	X

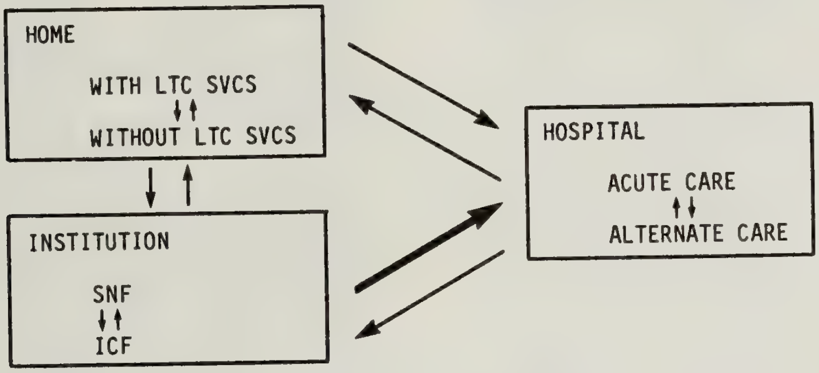
* NATIONAL STUDY WILL ALSO UTILIZE MEDICARE RECORDS FOR MORTAILITY AND READMISSION DATA.

RATES, PREDICTORS, CAUSES AND COSTS OF HOSPITALIZATION OF NURSING HOME RESIDENTS

William H. Barker, James G. Zimmer, and W. Jackson Hall, University of Rochester;
Brian Ruff, and Gerald M. Eggert, Monroe County Long Term Care Program.
(Supported by Grant AG05423 awarded by The National Institute on Aging)

The paradigm below (Figure 1) portrays various major transitions between home, hospital and long-term care (LTC) institutions which may occur in the health care careers of elderly persons with chronic illness. All such transitions tend to be costly and potentially detrimental to the well-being of elderly persons, hence important to health service research and policy-making. Much attention has been devoted to transfer from hospital to nursing home. There is, however, a relative dearth of information on transfers of nursing home residents to hospital, the pathway designated with the heavy arrow and the subject of the present study.

FIGURE 1
MODEL FOR STUDYING UTILIZATION OF HEALTH SERVICES BY CHRONICALLY ILL AND ELDERLY



The magnitude of the problem may be crudely estimated from the 1977 National Nursing Home Survey: 340,000 discharges to hospital among 1,400,000 nursing home beds, yielding a ratio of some 242 hospitalizations per 1000 longterm care beds per year.(1) Similar ratios have been noted in Monroe County, N.Y.(2) and in a study reported from Vancouver, British Columbia.(3) With these few exceptions, most available data sets on nursing home populations are from cross-sectional surveys and are of limited value in studying intercurrent events such as hospitalizations. For this purpose, longitudinal survey data are required.(4) The dearth of information on hospitalization from nursing home populations may be ascribed in part to the lack of data systems which link hospital and nursing home utilization. This in turn is a reflection of a larger issue - the historic separation between financing and organization of acute and long-term care in the United States.(5)

The goals of the present study are as follows:

1. To establish data sets and methods for the longitudinal study of hospitalization among nursing home residents.
2. To determine the association between selected admission characteristics of nursing home residents and the risk of subsequent hospitalization.
3. To compare hospitalization rates and characteristics of nursing home residents with hospitalization of community dwelling elderly persons.
4. To consider implications of the findings for alternative approaches to delivering medical care to nursing home residents.

MATERIALS AND METHODS

Setting

The setting of the study, Monroe County, N.Y. is briefly compared to the larger universe in Table 1. Some 11% of the population is over 65 y/o as in the U.S. at large. The ratio of general hospital beds per 1000 persons is somewhat smaller than that for the country, while nursing home (NH) beds per 1000 over age 65 are slightly more plentiful in Monroe County. The certification of nursing home beds is approximately 30% intermediate care (ICF) and 70% skilled nursing facilities (SNF) in both county and country.(6) Specifically in Monroe County in 1982 there were 32 SNFs with some 3600 beds and 11 ICFs with some 1400 beds. (Definition of ICF and SNF is provided in Appendix A).

Study Design

Figure 2 on the following page depicts the elements of the longitudinal study design which was used. The left box represents the study cohort which consisted of all new NH admissions in Monroe County in 1982. Below this are listed various easily identified admission characteristics included in analyses. The righthand box represents the dependent variable, all hospitalizations occurring among members of the 1982 cohort for up to two full years from time of

FIGURE 2
RATES, CAUSES, COSTS, PREDICTORS OF HOSPITALIZATIONS
OF NURSING HOME (NH) RESIDENTS

MODEL FOR STUDY

ALL NURSING HOME RESIDENTS ADMITTED 1982 → **HOSPITALIZATIONS (2 YEAR FOLLOW-UP)**

ALL NURSING HOME RESIDENTS ADMITTED 1982	HOSPITALIZATIONS (2 YEAR FOLLOW-UP)
DEMOGRAPHY	PRINCIPAL DIAGNOSIS
MEDICAL CONDITIONS	LENGTH OF STAY
ADL FUNCTION	COST
MENTAL STATUS	DISCHARGE STATUS
NH CHARACTERISTICS	

admission to NH. Data collected on hospitalizations are shown below this box.

Data Sources

A number of data sources were used. The principal source for identifying and characterizing the study cohort was the computerized nursing home utilization review file maintained by the Monroe County Long Term Care Program (ACCESS), one of the first and best known community-wide long-term care case management agencies in the country. (7) Chronic medical conditions, which were not included in the ACCESS computerized records, were obtained from written utilization review forms by the Genesee Valley Medical Foundation, a non-profit agency which conducts utilization review in nursing homes in Monroe County. The principal data source on hospitalizations was the New York State Uniform Billing Form routinely used by all acute care hospitals. Copies of these forms, which are compiled at time of hospital discharge, were obtained by a research assistant with the cooperation of the eight acute care hospitals in Monroe County. Data available from the National Nursing Home Survey, the Finger Lakes Health Systems Agency, and from INFOMED, a data management agency affiliated with the Rochester Area Hospital Corporation, were used for purposes of comparing the study cohort's experience with that of the country at large and of the general population over age 65 in Monroe County.

The study population consisted of some 2120 nursing home admissions during calendar year 1982, 1700 to SNFs and 420 to ICFs. Sex and age distributions were typical for nursing home populations, with preponderance of women and persons over age 80. Average length of stay during the 2 year period of follow-up was 402 days for SNF residents and 376 days for ICF.

Analysis

Preliminary analyses, as of July 1987, include:

1. Rates Overall rates of hospitalization and rates of hospitalization adjusted for time at risk, expressed per 1000 resident-years.
2. Predictors Univariate analyses of the association between characteristics present at admission to nursing home (See Figure 2) and the subsequent occurrence of hospitalization and stepwise regression analysis to determine amount of variance in hospitalization accounted for by specific admission characteristics.
3. Causes and Costs Distribution of hospitalizations by principal discharge diagnoses, average length of stay and average cost for all hospitalizations.

Data are analyzed separately for SNF and ICF cohorts and compared with national or communitywide data.

RESULTS

Table 2 summarizes overall frequency of hospitalization. While 30% of all subjects experienced at least one hospitalization, the percentages differed markedly between type of nursing home: 27% for SNF versus 42% for ICF. Some 9% of SNF and 13% of ICF subjects experienced multiple discharges to hospital. Table 3 contains counts of all hospitalizations and total resident years at risk for the SNF and ICF subgroups. Rates of hospitalization adjusted for time at risk are shown on the bottom line. The SNF-ICF difference persists with rates of 346 and 566 hospitalizations per 1000 resident-years, respectively. Cumulative percent of hospitalization over time are shown in Table 4. Patterns were very similar for SNFs and ICFs, with almost 40% of hospitalizations occurring within the first 90 days and 75% within the first year in both settings.

Predictors

Table 5 examines the association between individual baseline characteristics of study subjects at time of nursing home admission and subsequent hospitalization. For reference, the top line repeats the overall percent hospitalized for SNF and ICF subgroups, 27% and 42% respectively. Source of admission or transfer to nursing home, whether from hospital, another long-term care facility or home was not associated with greater or lesser risk of subsequent hospitalization. There was also little difference in subsequent hospitalization among age groups within either SNF or ICF except for slightly lower percents for the small number of residents under 65 y/o. Males had somwhat higher rates than females in SNFs, but somewhat lower

TABLE 1
SETTING - 1980 STATISTICS

	MONROE CO, N.Y.	U.S.A.
POPULATION	702,000	226×10^6
POPULATION $\geq$65 Y/O	77,000 (11%)	25.5×10^6 (11%)
HOSPITAL BEDS PER 1000	3.6	4.5
NURSING HOME BEDS	4,946	1.4×10^6
NURSING HOME BEDS PER 1000 $\geq$65 Y/O	65	60
SNF BEDS	70%	66%
ICF BEDS	30%	34%

TABLE 2
HOSPITALIZATIONS AMONG 1982 COHORT OF NURSING HOME (NH) ADMISSIONS BY PERCENT WITH ONE OR MULTIPLE HOSPITALIZATIONS

	TOTAL	SNF	ICF
NH ADMISSIONS	2120	1700	420
WITH ANY HOSP	626 (30%)	451 (27%)	175 (42%)
1 HOSP	436 (21)	315 (19)	119 (29)
2 HOSP	138 (7)	95 (6)	44 (10)
3+ HOSP	50 (2)	41 (2)	12 (3)

TABLE 3
HOSPITALIZATIONS AMONG 1982 COHORT OF NURSING HOME (NH) ADMISSIONS BY RESIDENT-YEARS AT RISK

	TOTAL	SNF	ICF
NH ADMISSIONS	2120	1700	420
TOTAL RESIDENT-YEARS	2303	1869	433
ALL HOSPITALIZATIONS	892	647	245
HOSPITALIZATIONS PER 1000 NH ADMISSIONS	421	380	583
HOSPITALIZATIONS PER 1000 RESIDENT-YEARS	434	346	566

TABLE 4
CUMULATIVE PERCENT OF HOSPITALIZATIONS OF NURSING HOME RESIDENTS OVER TIME FROM DAY OF ADMISSION

	CUMULATIVE PERCENTAGES		
TIME IN DAYS FROM ADMISSION	TOTAL	SNF	ICF
1-30	17	18	14
31-60	28	29	25
61-90	38	38	36
91-180	56	56	56
181-360	74	75	70
361-540	87	88	85
541-720	100%	100%	100%

TABLE 5
PERCENT OF 1982 NURSING HOME (NH) ADMISSIONS WITH ONE OR MORE HOSPITALIZATIONS BY SELECTED ADMISSION CHARACTERISTICS

NH ADMISSION CHARACTERISTICS	TOTAL WITH CHARACTERISTIC	(PERCENT WITH HOSPITALIZATION)
	SNF	ICF
ALL ADMISSIONS	**1700 (27)**	**420 (42)**
ADMITTED FROM		
HOSPITAL	1160 (28)	140 (43)
FACILITY	236 (26)	109 (39)
HOME	304 (23)	171 (42)
AGE		
<65	92 (18)	30 (37)
65-74	254 (25)	50 (52)
75-84	603 (29)	150 (43)
85+	751 (26)	190 (39)
SEX		
FEMALE	1264 (25)	323 (44)
MALE	436 (30)	97 (37)
CHRONIC CONDITIONS		
CARDIAC MISC.	695 (29)	197 (44)
CVA	312 (28)	47 (40)
CANCER	150 (23)	32 (50)
DIABETES	232 (31)	54 (44)
ARTHRITIS	367 (28)	131 (44)
HIP FRACTURE	237 (26)	34 (47)
COPD	120 (28)	39 (54)
G.I. DISEASE	109 (33)	27 (48)
PARKINSON'S DISEASE	72 (26)	13 (46)
SEIZURE DISORDER	64 (22)	12 (50)
DEMENTIA	464 (28)	79 (38)
DEPRESSION	84 (36)	46 (50)
FUNCTIONAL STATUS		
AMBULATION		
1	585 (27)	
2	1052 (28)	
3	64 (11)	
URINARY CONTINENCE		
1	717 (24)	
2	288 (28)	
3	581 (30)	
4 (CATHETER)	164 (23)	
BATHING		
1	117 (28)	
2	1279 (27)	
3	304 (23)	
VISION		
1	637 (25)	
2	921 (26)	
3	140 (32)	
IMPAIRED JUDGEMENT		
1	521 (24)	
2	657 (30)	
3	522 (25)	
ASSAULTIVE-ABUSIVE		
1	1565 (27)	
2	91 (27)	
3	44 (16)	
WANDERING		
1	1480 (26)	
2	109 (28)	
3	111 (28)	

NOTE

Functional Status not shown for ICF residents; most are independent or minimally impaired

Scales reflect:
1. Independent, Unimpaired
2. Partial Dependence or Impairment.
3. Total Dependence or Impairment.

rates in ICFs. Among chronic medical conditions present at time of admission to long-term care, diabetes, G.I. disease and depression were associated with somewhat higher risk of subsequent hospitalization for SNF residents while cancer, COPD, seizure disorder and depression were associated with higher risk for ICF residents. Analysis by functional status (conducted for SNF residents only) revealed little association with risk of hospitalization with the exception of the lower rates noted for the small number who were either totally bedfast (ambulation status 3) or markedly assaultive-abusive and a somewhat increased rate for those with total visual impairment.

Initial stepwise regression analysis of hospitalization rates failed to find groups of characteristics or single characteristics among those listed in Table 5 which would account for any meaningful proportion of the variance.

Causes and Costs

Table 6 shows distribution of hospitalizations among major principal discharge diagnosis groups. The most common principal diagnosis groups are compared between hospitalizations of elderly persons from NH and from the community, 790 of the former, 24,891 of the latter. Noteworthy are the greater proportions for cardiovascular and neoplastic disease hospitalizations among community elderly and of pneumonia and hip fracture among NH residents. Overall average lengths of stay in hospital were approximately one day longer (14.4 v 13.2) and average costs slightly higher for elderly persons admitted from nursing homes than for those from the community. (Table 7) These figures showed interesting reverse trends when analyzed for age subgroups, with the younger nursing home residents and the more elderly community-dwelling persons experiencing the longer and costlier hospitalizations within their respective populations.

An estimated overall cost of hospitalizations among this population of elderly persons newly admitted to nursing homes, utilizing data from Tables 3 and 7 (434 hospitalizations/1000 resident years x $5,850/hospitalization), comes to $2,538,900 (1983 dollars) per 1000 resident years.

SUMMARY AND DISCUSSION

In summary, this study has succeeded in establishing a cohort of nursing home admissions for the stated purposes of examining rates, predictors, causes and costs of hospitalization. An interesting and most salient finding in preliminary analysis is the markedly higher rate of hospization among residents of intermediate versus skilled care facilities. Given the high prevalence of chronic medical conditions with risk of acute complications among both ICF and SNF residents. explanations for the higher rate of

TABLE 6
DISTRIBUTION OF HOSPITALIZATIONS OF PERSONS>65 Y/O FROM NURSING HOMES AND FROM COMMUNITY BY PRINCIPAL DISCHARGE DIAGNOSIS

	PERCENTAGES	
PRINCIPAL DISCHARGE DIAGNOSIS	N. HOMES (N=790)	COMMUNITY* (N=24,891)
CARDIOVASCULAR	15%	22%
G.I. AND HEPATIC	13	12
PNEUMONIA	10	3
HIP FRACTURE	9	2
G.U. TRACT	7	6
NEOPLASM	5	13
EYE (CATARACT)	4	8
ALL OTHER	37	35

*Monroe County 1983

TABLE 7
AVERAGE LENGTH OF STAY AND COST OF HOSPITALIZATIONS OF ELDERLY PERSONS FROM NURSING HOME AND COMMUNITY

	N. HOMES			COMMUNITY		
AGE GROUP	N	AV. LOS	AV. $	N	AV. LOS	AV. $
65-74	94	15.2	5,812	12,586	11.5	5,373
75-84	320	15.4	6,312	9,046	13.8	5,667
85+	345	13.5	5,529	3,259	17.8	6,133
All 65+	759	14.4	5,849	24,891	13.2	5,580

(Note: Data for above unavailable on approx. 8% of hosp. from N. Homes) hospitalization among the former may be speculated upon. A leading likelihood is that the lesser degree of medical and nursing supervision in ICFs leads to a need to transfer unstable residents to hospital more often than would be necessary from the better-staffed SNF. (See Appendix A) Conversely, given the heavier degree of compromising disability among SNF residents, it may be that heroic medical intervention, including transfer to hospital when acutely ill, is withheld more often among these residents by mutual consent of attending physicians and residents or their relatives.

With respect to the quest for predictors of hospitalizations, based upon many identifiable characteristics present at time of admission to NH, analysis of such characteristics, individually and in preliminary stepwise regression, have been relatively unrevealing. This experience reflects the increasingly apparent heterogeneity of the long-term care population (4) and in turn the need for a more discriminating basis for classification of subgroups, such as the "grade-of-membership" approach described elsewhere at this conference.(8)

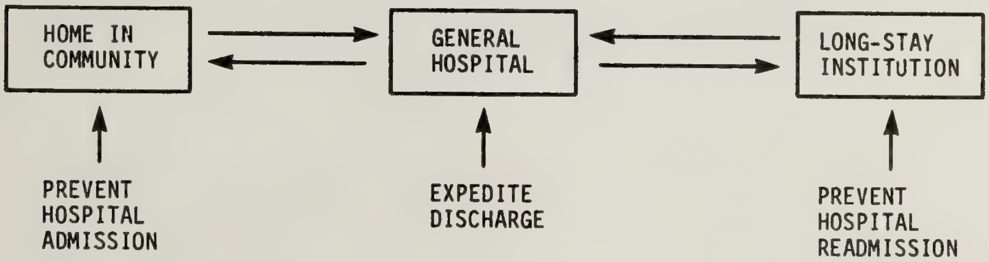
The causes and costs of hospitalization from nursing homes are, with some notable exceptions, quite similar to the experience of community-dwelling elderly- exceedingly high utilization of hospitals.

This leads to consideration of implications of these data for the delivery of medical care to nursing home residents. Specifically, I should like to briefly touch on several alternative approaches which have been shown to reduce costly and traumatic transfers to hospital without compromising quality of care. First is more vigorous provision of clinical care within nursing homes, particularly through the modality of gerontologic nurse practitioners working in association with physicians. (9) Second is the use of financial incentives to physicians and nursing home staff to manage acute episodes on site rather than transfer to a hospital.(10) Third is the active engagement of physicians, nurses, NH residents and/or family in deciding on guidelines to be followed in the event of a life-threatening illness.(11) All three of these alternatives have been successfully employed in special projects in this country; however they are distinctly out of the ordinary and usually depend upon special waivers.

In closing, I would focus on the role of health service organization, and suggest that herein lies the most important alternative to the high use of hospital by NH residents. In essence, the administrative separation between the acute care hospital sector and long-term care nursing home sector in the U.S. health care system leads each to transfer elderly patients back and forth, respectively, on grounds of being either too chronic or too acute.

Figure 3 depicts an organizational model in which the several loci of medical care are administratively and professionally linked - the British National Health Service. Specifically with reference to care of the frail elderly, geriatric medicine departments play an active role not only within the general hospital but in visiting high risk elderly patients in the community and in long-stay institutions, with resultant prevention of many would-be hospitalizations. (12) In meeting the continuing care needs, hospital utilization in particular, of the inveitably growing population of institutionalized elderly, this country might do well to emulate features of the organizational model of geriatric medicine in Great Britain. Definition of the magnitude and pattern of utilization, as has been undertaken in the present study, should help to focus such consideration on the part of health policy-makers.

FIGURE 3
POINTS OF INTERVENTION BY GERIATRICS DEPARTMENTS TO REDUCE HOSPITAL UTILIZATION



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APPENDIX A
DEFINITIONS OF SKILLED AND INTERMEDIATE CARE FACILITIES BY LEVEL OF CARE, MEDICAL CARE, UTILIZATION REVIEW

SKILLED NURSING FACILITY (SNF)

1. RESIDENTS WITH CHRONIC MEDICAL CONDITIONS AND DISABILITIES REQUIRING CARE OF SKILLED TECHNICAL/PROFESSIONAL PERSONNEL.
2. PHYSICIAN VISIT AT ADMISSION AT 30 OR 60 DAY INTERVALS
3. UTILIZATION REVIEW AT REGULAR INTERVALS

INTERMEDIATE CARE FACILITY (ICF)

1. RESIDENTS WITH CHRONIC MENTAL OR PHYSICAL CONDITIONS REQUIRING HEALTH-RELATED INSTITUTIONAL SERVICES, BUT NOT SKILLED CARE.
2. PHYSICIAN VISITS AT 60 OR 90 DAY INTERVALS
3. UTILIZATION REVIEW AT REGULAR INTERVALS

(FROM FEDERAL CERTIFICATION STANDARDS)(13)

Session L

Issues in Reporting Cause of Death on the Death Certificate

DATA FOR AN AGING POPULATION

The Impact of Death Certificate Validity on Coronary Heart Disease Mortality Trends: The Minnesota Heart Survey

Gregory L. Burke, Aaron R. Folsom, Richard S. Crow,
Stanley A. Edlavitch, J. Michael Sprafka, University of Minnesota

Introduction

Coronary heart disease mortality rates have declined at an average rate of 2-3% per year in the United States from the mid-1960s to the present (1,2). Despite this decline, coronary heart disease (CHD) remains the leading cause of death in both men and women. The Minnesota Heart Survey has been assessing trends in coronary heart disease morbidity, mortality, and risk factors in the Twin Cities to determine the relative contribution of prevention and clinical care on the overall decline in CHD mortality since 1968 (3,4). One part of the surveillance effort has been to validate out-of-hospital coronary heart disease deaths which have occurred in Twin Cities residents, to verify that changes in vital rates reflect the actual CHD mortality experience in the community. Out-of-hospital deaths were chosen because they are often difficult to classify due to less information available for determining the cause of death. In addition, since a large portion of the decline in CHD mortality has occurred in out-of-hospital events (5-7), it is important to assess the location of death to ensure that changes in rates of hospitalized MI deaths are real and not simply due to changes in the number of cases being transported to the hospital by the emergency medical system.

This paper describes trends in coronary heart disease mortality from 1960 through 1985 in Twin Cities residents. The relative importance of in-hospital versus out-of-hospital deaths on the declining rate of CHD since 1968 is discussed. Results from a validation study of out-of-hospital coronary heart disease deaths in 1979 are also presented.

Methods

Data Collection

Data are presented for individuals ages 30 to 74 years who were residents of the seven-county Twin Cities metropolitan area. Mortality rates from 1960 to 1985 were analyzed for Twin Cities residents from death tapes obtained from the Minnesota State Department of Health. Age-specific population estimates were derived from census data for Minnesota in 1960,1970, and 1980. Intracensal estimates from 1960 to 1980 were made by linear interpolation. From 1981 to 1985 population estimates from the National Cancer Institute were used. Information pertaining to location of death (i.e., in-hospital versus out-of-hospital) first became available on death tapes in 1968 and is presented for Twin Cities residents from 1968 through 1985.

The out-of-hospital deaths for coronary heart disease were validated on a 33% sample of 1979 deaths selected from a broad range of cardiovascular, cardiopulmonary, or nonspecific death certificate codes. These codes represent a broad spectrum of disease and essentially are comprised of all cases except for those deaths due to cancer, trauma, or violent causes.

Death Certificate Codes Used

In assessing CHD mortality trends from 1960 through 1968, CHD was defined as those deaths with the underlying cause death certificate code (ICD-7) of 420, from 1969 through 1978 (ICD-8) 410-413, and from 1978 through 1985 (ICD-9) 410-414. In addition, because CHD often was assigned to "natural causes" in this community we assessed trends over time using code 795 in ICD-7, 796 in ICD-8, and 799 in ICD-9. Previous reports have shown good reliability between CHD and "natural causes" codes from ICD-7 to ICD-8 and from ICD-8 to ICD-9 (8,9).

Validation of Out-of Hospital Deaths

A 33% sample of out-of-hospital deaths was randomly selected by having a trained clerk review all 1979 death certificates. Eligible deaths included emergency room events, "dead on arrival" to the hospital, and any deaths which occurred outside the hospital. Out-of-hospital deaths were validated by contacting the informant listed on the death certificate and obtaining information about the decedent's prior history of heart disease, previous hospitalizations, and details of symptoms and events around the time of death. In addition, secondary data sources including autopsy reports, physician records, hospital records, and nursing home records were obtained when available.

Once all available data were collected, a study physician reviewed the information to assign cause of death using standardized criteria. Cases were placed into one of five categories as has been described in detail previously (10). Briefly, the hierarchical categories are:

A) Definite fatal MI, defined as death from a myocardial infarction (confirmed by chest pain, cardiac enzyme, electrocardiography, or autopsy criteria) in the absence of a non-cardiac cause of death.

B) Definite sudden death, defined as 1) a death within one hour of severe coronary heart disease or symptoms or being observed free of symptoms, 2) in the absence of a definite MI or a non-cardiac atherosclerotic cause of death.

C) Definite fatal CHD, defined as 1) a death within 24 hours of severe coronary heart disease symptoms or 2) a death with a previous history of MI or severe coronary heart disease, and 3) incompatible with our criteria of definite MI, sudden death or non-cardiac cause of death.

D) Possible fatal CHD, defined as 1) a death with death certificate codes of CHD (410-414 or 427.5) and 2) incompatible with our criteria of definite MI, sudden death, fatal CHD or non-cardiac cause of death.

E) Non-CHD were those deaths not meeting any of the above criteria.

Statistical Analyses

To assess mortality trends of coronary heart disease from 1960 through 1985, yearly rates per million were calculated and directly age-standardized to the 1970 U.S. population. Percent agreement was used to compare the physician-validated diagnosis to the death certificate diagnoses of CHD. Sensitivity and specificity of death certificate diagnosis of CHD were calculated using the physician-validated diagnosis as the gold standard. A death certificate diagnosis code of 410-414 and 427.5 was assumed to represent coronary heart disease, and the codes on these certificates were contrasted with the physician diagnosis of CHD or non-CHD.

Results

The age-adjusted trend in coronary heart disease mortality for Twin Cities residents ages 30 to 74 years is presented in figure 1. Rates in coronary heart disease mortality in the Twin Cities peaked in approximately 1968 and have declined consistently into the early 1980s. From 1968 to 1985 there was a 50% decline in coronary heart disease mortality rates in men with a 46% decline in women.

Out-of-hospital deaths (i.e., non-hospital and DOA deaths) contributed more to the overall decline in CHD mortality rates between 1968 and 1985 than did in-hospital deaths. Although both in-hospital and out-of-hospital CHD rates declined since 1968, in-hospital rates in women declined by 26% , whereas out-of hospital rates declined by 59%. In men, in-hospital CHD rates declined by 17% while out-of-hospital rates declined by 71%.

Table 1 shows the availability of data for validating out-of-hospital fatalities in 1979. A total of 413 deaths were selected for validation. An informant interview was obtained in 77% of these cases, autopsies were done on 24%, a physician questionnaire was returned on 37%, nursing home records were available on 6%, and hospital records were available on 23% of the decedents. In 18% of the cases, no autopsy or informant interview was available. The remainder of the validation data presented concentrates on the 339 cases where at least an autopsy or informant interview were available in addition to the death certificate. These cases were similar in age, sex, and death certificate diagnoses to those on whom data were available, so their exclusion should not bias the validation.

Table 1

Data Availability for Validation of Out-of-Hospital CHD Deaths in Twin Cities Residents: Minnesota Heart Survey

Source	N	%
Informant Interview	319	77
Autopsy	98	24
M.D. Questionnaire	151	37
Nursing Home Record	25	6
Hospital Record	93	23
Death Certificate Only	74	18

Table 2 shows the comparison of physician-validated categories to the death certificate diagnoses.

Table 2

Comparison of Physician Validated Deaths to Death Certificate Diagnoses: Minnesota Heart Survey

MD REVIEW DIAGNOSIS	(%)	DEATH CERTIFICATE CHD*	NON-CHD
DEFINITE MI	(8)	28	6
DEF. FATAL CHD	(25)	69	15
POSS. FATAL CHD	(6)	18	3
NON-CHD	(24)	14	67
UNCERTAIN	(3)	1	10

*ICD-9 codes 410-414, 427.5.

Eight percent of the cases were defined as definite MI by our criteria and all of them were categorized as CHD by death certificate. Thirty-four percent of the cases were categorized as sudden deaths with 95% of those cases having a CHD diagnosis on the death certificate. Twenty-five percent of the cases were categorized as definite fatal CHD; 82% of these cases were categorized as CHD by death certificate. Possible fatal CHD comprised 6% , and 86% of those cases were categorized as CHD on death certificate. Twenty-four percent were due to causes other than coronary heart disease , and only 17% of those cases had coronary heart disease listed as the cause of death on the death certificate. To determine sensitivity and specificity of the death certificate diagnosis of coronary heart disease, the validated definite MI, sudden death, definite fatal CHD and possible fatal CHD categories were combined into an overall CHD category. Using the physician validated diagnosis as the standard,the sensitivity of a death certificate diagnosis for coronary heart disease (i.e., 410-414, 427.5) was 90% with a specificity of 83%. In more than 50% of cases with a non-CHD code on the death certificate where CHD was validated by our physician review, "natural causes" was listed as the underlying cause of death.

The rate of deaths coded as "natural causes" by death certificate in Hennepin and Ramsey Counties, where the cities of Minneapolis and St. Paul are located, was compared to the entire state of Minnesota from 1960 through 1985 (figure 2). The mortality rate from "natural causes" was relatively constant from 1960 through 1970 and began to increase rapidly, especially from the late 1970s through the early 1980s. The number of deaths coded as "natural causes" in Hennepin County has consistently been above that for the entire state of Minnesota. In more recent years, Ramsey County has also had an increase in the number of deaths coded as "natural causes". To assess if increased numbers of deaths coded to "natural causes" artificially caused the decline in coronary heart disease rates in the Twin Cities, trends in coronary heart disease were compared with trends in coronary heart disease plus "natural causes" deaths (figure 3). Although the decline is slightly blunted in more recent years, the trend is virtually identical whether CHD is assessed by itself or with "natural causes" mortality included. Rates for CHD mortality in men decreased by 50% from 1968 to 1985 versus 48% when "natural causes" was included, while in women CHD mortality decreased by 45% versus 43% with "natural causes" included. The decline in coronary heart disease mortality persists regardless of the potential confounding impact of recent increased use of "natural causes" codes in the Twin Cities.

Discussion

These data show an overall decline in coronary heart disease mortality rates from 1968 through 1985 for men and women in the Twin Cities metropolitan area. Mortality trends in Minnesota are similar to those in other national and regional studies (2). In addition, we have noted that a large part of the decline in CHD mortality occurred in out-of-hospital deaths. The greater decrease in out-of-hospital deaths most likely reflects a combination of improved primary prevention, emergency medical services, and better medical care for patients with previously diagnosed CHD. A similar disproportionate improvement in out-of-hospital CHD rates has been documented in other communities (11,12).

The study of out-of-hospital CHD deaths in the Twin Cities metropolitan area show a high degree of agreement between CHD on death certificates and our validated diagnoses. Two studies conducted in Louisiana and Ontario on the validity of death certificate CHD mortality diagnoses prior to 1964 showed a substantial degree of misclassification. A more recent investigation by Kuller and his colleagues in young men from Allegheny County, Pennsylvania described results similar to ours (6). They found a sensitivity of 98% and specificity of 75% for CHD diagnosis on death certificates (using the physician review as the standard).

One coding practice peculiar to the Twin Cities was the use of "natural causes" coding as an underlying cause of death. These cases were primarily deaths investigated by the medical examiners offices in the Twin Cities. The impact of the increased use of "natural causes" coding in cases with ambiguity in the etiology of death has not altered the long-term trends of declining CHD mortality rates in the Twin Cities. These cases currently comprise less than 5% of our physician validated CHD deaths, but should this percentage increase, this category could artificially alter vital rates of CHD based on ICD-9 codes of 410-414.

In conclusion, we noted a high degree of concordance between our physician validated diagnoses using standard criteria and death certificate diagnoses of CHD (13). In more than half of the CHD deaths validated in our study with non-CHD codes on the death certificate "natural causes" was coded. However this group comprises such a small percent of the total CHD cases that the overall trends from 1968 to 1985 were uneffected. Periodic validation of death certificate diagnoses should be conducted to insure that community trends in CHD mortality are accurately reflected in the vital statistics data.

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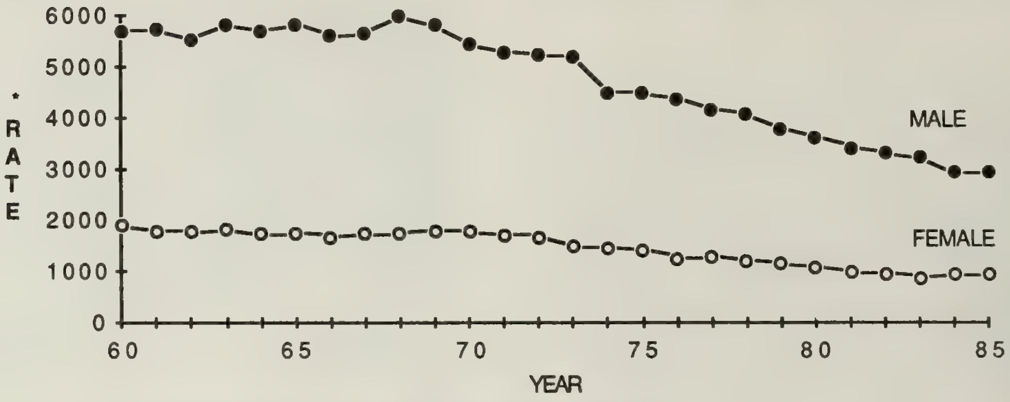
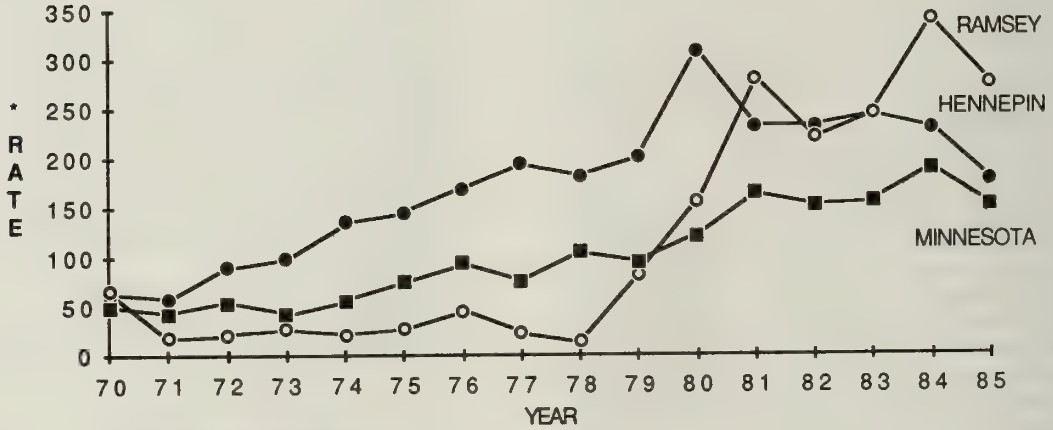
FIGURE 1. CORONARY HEART DISEASE MORTALITY RATES FROM 1960-1985 IN 30-74 YEAR OLD TWIN CITIES RESIDENTS: MINNESOTA HEART SURVEY



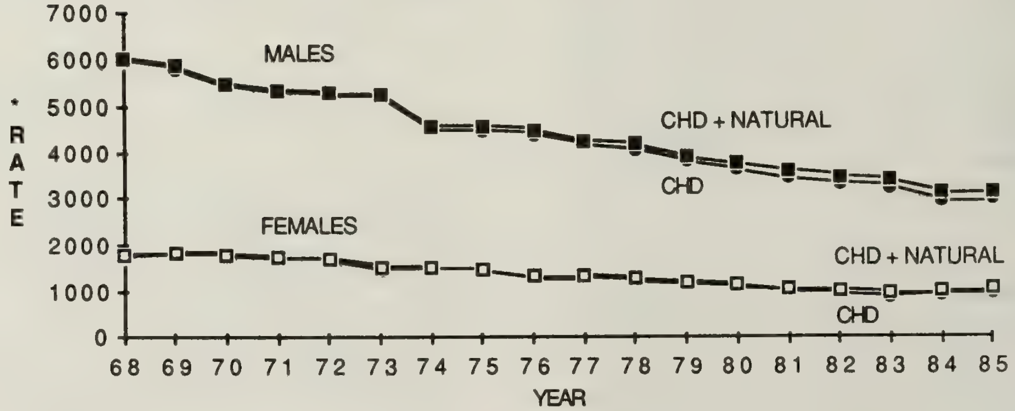
* AGE-ADJUSTED TO 1970 US POP (PER MILLION)

FIGURE 2. MORTALITY RATES FROM NATURAL CAUSES IN MALES AGES 30-74 YEARS:MINNESOTA HEART SURVEY



* PER MILLION PERSONS

FIGURE 3. CHD MORTALITY RATES INCLUDING AND EXCLUDING "NATURAL CAUSES" IN 30-74 YEAR OLD TWIN CITIES RESIDENTS: MINNESOTA HEART SURVEY



* AGE ADJUSTED TO 1970 US POP (PER MILLION)

METHODOLOGIC ISSUES IN THE REPORTED PREVALENCE OF ALZHEIMER'S DISEASE ON DEATH CERTIFICATES

Ronald Aubert, Robert Parker, Richard Rothenberg, Daniel May
Centers for Disease Control

Introduction

In many industrialized countries, as the elderly population has increased, Alzheimer's disease has become more and more prevalent. Community surveys show an estimated prevalence of 2.5% in persons over the age of 65 (1). Despite the frequency of this condition, no national data are available for measuring the incidence, prevalence, or contribution to mortality of Alzheimer's disease. To measure the reported prevalence at death of Alzheimer's disease and to characterize its descriptive epidemiology, we used death certificate data to provide information on trends in the reported prevalence at death.

In addition to recording the primary cause of death, the death certificate also requests that conditions related to death and other significant conditions, which contribute to but do not necessarily relate to the cause of death, be listed. This supplementary information is important when mortality related to chronic diseases is being studied. Given the complex etiologies of many chronic diseases, reporting one primary cause of death is inadequate and will inevitably underestimate the public health importance of conditions that are not considered the primary cause of death.

Recognizing a growing need for multiple-cause-of-death statistics, the National Center for Health Statistics routinely began coding all conditions on the death certificate, and multiple-cause-of-death data from 1968 are now available. Given the dearth of information on national estimates of Alzheimer's disease and the increasing importance of health issues relating to an aging population, we conducted this study with the following objectives in mind:

(1) To explore the potential of multiple-cause-of-death data as a surveillance tool by estimating the reported prevalence at death of Alzheimer's disease.

(2) To consider the effect of using different denominators on estimating the reported prevalence at death of Alzheimer's disease.

(3) To use the reported prevalence at death as our basic measure of occurrence to characterize the descriptive epidemiology of Alzheimer's disease, including geographic variability and changes in the reported prevalence at death of Alzheimer's disease.

(4) To assess the contribution of a diagnostic shift to the reported increase in Alzheimer's disease: specifically, to determine whether there was evidence of a diagnostic shift from the broader category of senile dementia to the more specific diagnosis of Alzheimer's disease.

(5) To assess whether or not an increased reporting of the number of conditions on the death certificate contributes to the reported increase in Alzheimer's disease.

Our primary source of information was the multiple-cause-of-death data tapes from 1968 to 1983. Each condition of the death certificate is listed on these tapes, in the order in which it appears on the death certificate as a disease entity (referred to as "the entity axis"). Conditions then undergo a systematic editing and translation of codes (combining codes, dropping codes, or adding new codes) to resolve ambiguities (2). These edited codes are listed in ascending order in the record axis.

Methods

Alzheimer's disease was defined by International Classification of Diseases (ICD) code 290.1 (8th revision) for the years 1968-1978 and by ICD code 331.0 (9th revision) for the years 1979-1983. Demographic characteristics such as age, race, gender, and residence information were used for subgroup analysis.

Our study population was restricted to persons 50 years of age and over who had a residence in any of the 50 states or the District of Columbia. Numerators for reported prevalence rates were defined as any mention of Alzheimer's disease on the record axis.

Age- and sex-standardized reported prevalence-at-death rates were calculated on the basis of 1975 population estimates.

To assess age trends from 1968-1983, we used annual population estimates to calculate reported prevalence-at-death measures. For each period, we did comparative analyses, using the total number of deaths to assess the effect of different denominators.

Results

Looking at trends in the reported prevalence at death of Alzheimer's disease from 1968 to 1983, we see a consistent and gradual increase until 1979 (Figure 1). In 1980, however, the reported prevalence at death is 44% higher than it was in 1979 (2.7/100,000 in 1979 to 3.9/100,000 in 1980). In 1981 the reported prevalence at death of Alzheimer's disease is 41% higher than in 1980 (5.5 vs. 3.9), and in 1982 it is 49% higher than in 1981. In 1983 we see a reported prevalence at death 84% higher than that observed in 1982. This gives a fivefold increase over 5 years compared with a threefold increase between 1968 and 1978. The reported prevalence at death was, therefore, nearly 19 times higher in 1983 than it was in 1968.

The reported prevalence at death of Alzheimer's disease was calculated by using population estimates for four age, race, and sex groups. White males had a slightly higher reported-prevalence-at-death rate than did white females. Beginning in 1975 and continuing until 1983 (Figure 2), both showed parallel and consistent trends throughout the period. A similar pattern for males and females is seen among persons of races other than white between 1977 and 1982.

When we considered, however, the number of mentions of Alzheimer's disease relative to the total number of deaths, white females had a slightly higher (but a consistently higher) reported-prevalence-at-death rate than did white males (Figure 3). This may be explained by a more favorable life expectancy among females--in the older age groups,--the male population decreases much more rapidly than the female population. With the exception of 1982, there is no difference in the reported prevalence at death between males and females among persons of races other than white.

Next, we examined the trends of reported prevalence at death of Alzheimer's disease by age groups. Using population estimates as the denominator, we found what might be expected--that the reported prevalence at death increased by age group with the highest prevalence in the 80-and-over age group (Figure 4). This was most notable after 1979. In 1983, the reported prevalence at death was 86 times greater in the 80-and-over age category when compared with 50 to 59-year-olds, 10 times higher when compared with 60 to 69-year-olds, and 2.5 times higher when compared with 70 to 79-year-olds.

We observed a very different pattern, however, when we used the total number of deaths as a denominator to calculate the reported prevalence. From 1968 into the early 1970s, the proportion of persons dying with Alzheimer's disease was quite low in the older age groups (Figure 5); it was about 9 to 12 times higher in those under 70 than in those 70 and above. Although all age groups showed an increase in the proportion of those dying with a mention of Alzheimer's disease in the late 1970s and early 1980s, the increase was far greater in the older group. As Figure 5 shows, reported-prevalence-at-death rate crossovers occurred between older and younger groups during the 1977-1981 period, after which the prevalence at death in the 70-and-over group greatly exceeded that in the younger groups. This crossover may reflect a shift in the definition of Alzheimer's disease. Perhaps before 1977, Alzheimer's disease included a definition that was generally restricted to presenility and was seldom used in the older age groups. In 1983, there is little difference in the reported prevalence at death of Alzheimer's disease between the 80-and-over age group and the 70-79 age group. The reported prevalence at death is 1.7 times higher in the 80-and-older age group compared with 60-69 age group, and 6.5 times higher than the 50-59 age group. These estimates are much closer together than the estimates obtained by using the total population.

To assess geographic variability in the reported prevalence at death of Alzheimer's disease, we categorized the average annual state-reported prevalence rates into national tertiles (Figure 6). The black area on the map represents states with a reported prevalence at death in the lower tertile, the hatched areas represent the middle tertile, and the white areas represent the upper tertile. States in the upper national tertile tend to cluster in the Northeast and West. States with the highest average annual reported prevalence at death of Alzheimer's disease are Massachusetts (68/1,000,000); the State of Washington (55/1,000,000); and Maine, Ohio, and Oregon (49/1,000,000).

States with the lowest average annual reported prevalence at death are Hawaii (13/1,000,000), Arkansas and Louisiana, (15/1,000,000), and Mississippi and South Dakota (17/1,000,000).

When we assessed the geographic variation in the reported prevalence at death, using total deaths in the denominator, the patterns were consistent with few exceptions. Colorado and Iowa moved from the middle tertile to the upper tertile. Changes also occurred in the relative ordering of extreme values, but the patterns were consistent. (The highest reported-prevalence-at-death/rates of Alzheimer's disease were in the states of Massachusetts, Washington, Oregon, Arizona, and Maine. The states with the lowest reported-prevalence-at-death rates were Louisana, Arkansas, Mississippi, Hawaii, and Tennessee.)

Considering the period 1979-1983, when the highest reported-prevalence-at-death rates of Alzheimer's disease were observed, again we saw a familiar pattern. With the exception of Iowa, the reported prevalence-at-death rate is distributed as seen in the previous analysis, with population estimates.

One question arising from the consistent increase in the reported prevalence-at-death rate of Alzheimer's disease is whether this represents an actual increase in the disease or whether it reflects a diagnostic shift from senile dementia; is what was called "senile dementia" previously, now commonly being labeled "Alzheimer's disease"?

We plotted the reported prevalence at death of Alzheimer's disease and the reported prevalence at death of senile dementia to address this issue (Figure 7). From 1968 to about 1975 there appears to be a diagnostic shift contributing to an increasing occurrence of Alzheimer's disease; senile dementia decreases as Alzheimer's disease increases.

A diagnostic shift from senile dementia, however, cannot be considered the cause of the secular trend. Between 1968 and 1975, the reported prevalence at death of senile dementia decreased by 65 per million, whereas the reported prevalence at death of Alzheimer's disease increased by only 8 per million. In 1976, both senile dementia and Alzheimer's disease increased, ruling out the possibility that the increase in the reported prevalence at death of Alzheimer's disease results from a shift toward diagnosing Alzheimer's disease in favor of senile dementia. Another interesting observation is that all of the decline from 1968 to 1975 is due to the dramatic decrease in reported prevalence at death of senile dementia in one state--New York.

If we exclude the State of New York in plotting the trends, we do not see the decline in senile dementia (Figure 8). Again, this is further evidence for ruling out the possibility that a diagnostic shift from senile dementia to Alzheimer's disease caused the increase in the reported prevalence at death of Alzheimer's disease.

Another issue we addressed was whether the increasing trend in reported prevalence at death reflected a tendency to add more conditions on the death certificate. Perhaps Alzheimer's disease is a condition added in later positions on the death certificate, and the increase thereby reflects a secular trend of reporting more conditions. We plotted the distribution of the position on the entity axis in which Alzheimer's disease was mentioned and found only a slight shift from 1979 to 1983 (Figure 9). In 1979 Alzheimer's disease was mentioned most frequently in position 2 on the entity-axis, and in 1983, most frequently in position 3. Since there is not a shift in the later positions, the increasing trend in the reported prevalence at death of Alzheimer's disease cannot be attributed to an increase in the number of conditions reported.

Conclusions

In summary, in the United States, the reported prevalence at death of Alzheimer's disease has shown an overall increase. All four age, race, and sex groups show similar increasing patterns over time. Different conclusions might be drawn, however, depending on what is used as a denominator in calculating the reported prevalence at death.

The increase in the reported prevalence at death does not appear to reflect a diagnostic shift, with a preference for Alzheimer's disease over senile dementia, nor does it reflect a substantial increase in the number of conditions reported on the death certificate.

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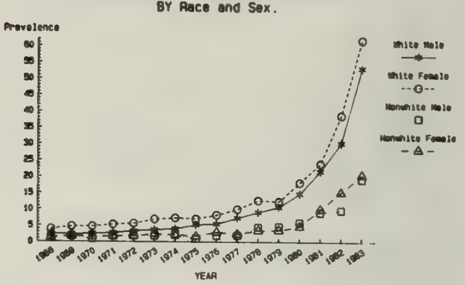
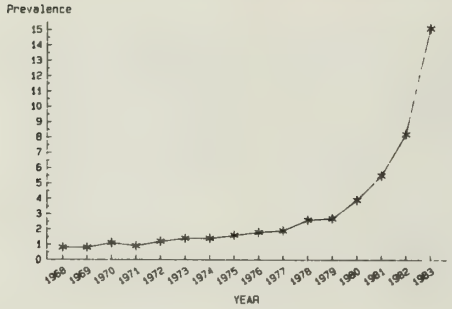


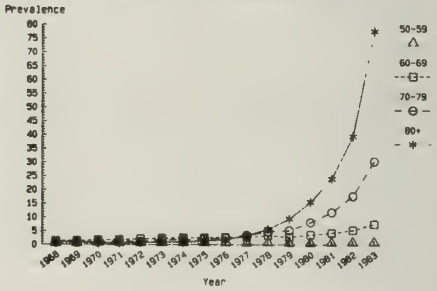
Reported Prevalence at Death of Alzheimer's Disease, per 10,000 Deaths, BY Race and Sex.

Figure 3



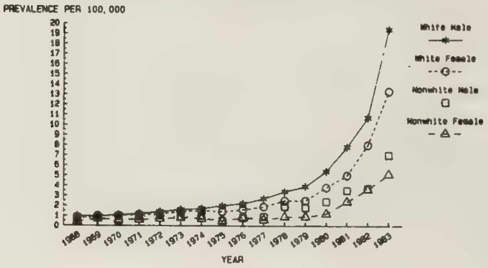
Reported Prevalence at Death of Alzheimer's Disease, per 100,000 Population, Standarized to 1975 Population

Figure 1



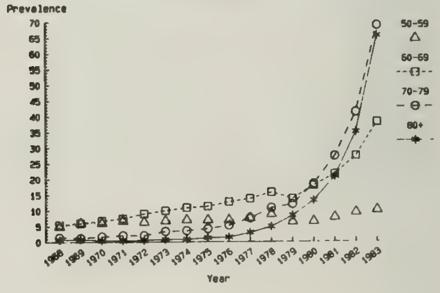
Reported Prevalence at Death of Alzheimer's Disease, by Age Group, Per 100,000 Population

Figure 4



Reported Prevalence at Death of Alzheimer's Disease, per 100,000 Population, Standardized to 1975 Population, by Race and Sex

Figure 2



Reported Prevalence at Death of Alzheimer's Disease, per 10,000 Deaths, By Age Group.

Figure 5

Average Annual Age-Sex Adjusted Reported Prevalence Rates Per 1,000,000 Population, United States, 1968-1983

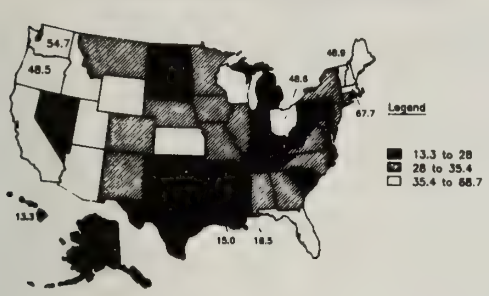


Figure 6

Reported Prevalence at Death of Senile Dementia and Alzheimer's Disease, Standardized to 1975 Population, per 100,000

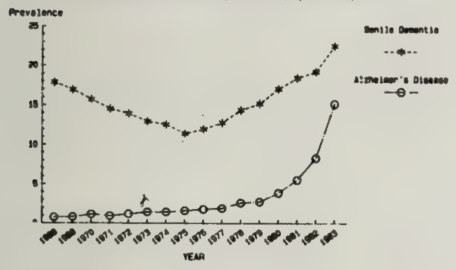


Figure 7

Reported Prevalence at Death of Senile Dementia and Alzheimer's Disease, Standardized to 1975 Population, per 100,000

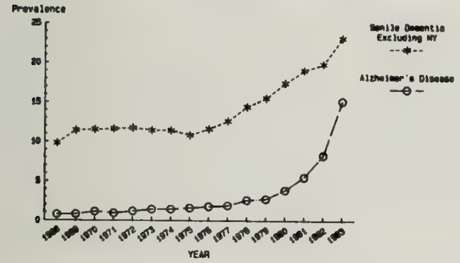


Figure 8

Distribution of Position on Entity Axis of Alzheimer's Disease Mention, By Year, 1979-1983

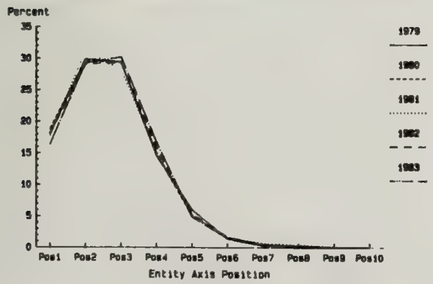


Figure 9

VALIDITY OF CAUSE-OF-DEATH REPORTED ON THE DEATH CERTIFICATE: ISSUES FOR PRESENT AND FUTURE

Tobias Kircher, Penrose Hospital, Colorado Springs, Colorado

Mortality statistics will undoubtedly remain a primary source for continuous monitoring of diseases in both the U.S. and world populations. Death certificates, in fact, continue to be one of the only continuously collected population-based sources of data for estimates of the incidence and prevalence for many diseases. Statisticians and epidemiologists have long recognized problems with the validity of cause-of-death on death certificates. Problems with the reliability of cause-of-death appear to be related to at least four areas: 1) the current state of medical knowledge, 2) incompleteness of the information available at the time of death, 3) the various ways in which death certificates are completed, and 4) the classification of underlying cause in the vital records system.

I would like to address these problems with the hypothesis that the accuracy of medical certification of cause-of-death can be improved, that these improvements will improve health care, and that current mortality statistics are very useful, but could be made more so if accuracy were increased.

Since 1923 when Wells challenged the reliability of existing cancer statistics, hundreds of publications documenting discrepancies between major clinical and autopsy diagnoses have repeatedly raised questions about the accuracy of published mortality statistics.[1] The questions and issues about quality, accuracy and validity have to do with the clinical diagnoses themselves and the medical certification, not the handling or compilation of the cause-of-death statistics. In fact, the entire local, state and national system is to be commended for its efficiency and precision in handling what it receives. The problems lie with the target - the accuracy of what is received. The tabulated data can be no better than the causes-of-death which certifying physicians write on death certificates. Even a compilation by NCHS in 1982 of cause-of-death validation studies stated that "little is known about the quality of medical certification and its effect on diagnostic statistics in general and on national cause-of-death statistics in particular".[2] Although the monograph felt that definitive conclusions about quality had not been reached based on studies published through 1980, the NCHS staff stated "the findings provide no basis for complacency".

Let us look briefly at several of these validation studies. Disagreement rates between clinical or death certificate underlying cause-of-death and autopsy cause-of-death have varied widely from 25-56%.[3] In a study by Goldman, 100 randomly selected autopsies from each of the academic years 1960, 1970, 1980 from one university hospital were analyzed to determine whether advances in diagnostic procedures had reduced the value of autopsies.[4] In all three eras, approximately 10% of the autopsies revealed a major diagnosis that, if known before death, might have led to a change in therapy and prolonged survival; another 12% showed a clinically missed major diagnosis for which treatment would not have changed (Table 1). It was concluded that advances in diagnostic technology have not reduced the value of the autopsy in establishing an accurate cause-of-death.

To determine the extent of agreement on underlying cause-of-death between death certificates and autopsy reports in Connecticut, we analyzed 272 randomly selected autopsy reports and corresponding death certificates from among all such data on autopsies performed in Connecticut in 1980.[3] In 29% of the deaths, a major disagreement on the underlying cause-of-death led to reclassification of the death in a different ICD major disease category (Table 2). In an additional 26%, the death certificate and autopsy report agreed on the major ICD disease category but attributed the death to a different specific disease, for example acute myocardial infarction changed to ruptured aortic aneurysm (intermediate match).

Agreement on underlying cause-of-death for three selected disease categories is shown in Table 3. Deaths due to neoplasms were most accurately diagnosed with a sensitivity of 87% and a major disagreement rate of 13%. Deaths resulting from diseases of the respiratory system were associated with the highest rate of disagreement, 67%. Circulatory disorders, with a disagreement rate of 18%, were one of the disease categories most commonly overdiagnosed.

The positive predictive value of the death certificate underlying cause-of-death for these three selected causes-of-death varied widely. In 85% of cases of cancer, the death certificate accurately stated the underlying cause-of-death. Circulatory disorders had a positive predictive value of 75%. For respiratory diseases, only 31% of death certificates correctly predicted the underlying cause-of-death.

In work from the University of New Mexico and Upstate Medical Center in Syracuse, published studies encompassing more than 50,000 autopsies were assessed to determine the sensitivity and specificity of clinical diagnoses in persons dying of one of eleven specific diseases during the period 1930-1977.* The accuracy of clinical diagnostics, as reflected in the sensitivity rate, appeared to improve over the years for diseases such as leukemia and rheumatic heart disease and worsened for others (Table 4). Pulmonary tuberculosis, peritonitis, and carcinoma of the liver were among those for which clinical diagnosis showed a worsening during the 50-year period. As shown by these figures for tuberculosis, the chance of finding clinically unsuspected pulmonary tuberculosis at autopsy has increased, not decreased. For diseases such as cirrhosis and acute coronary thrombosis/myocardial infarction, diagnostic accuracy has seemed refractory to sustained change.

The authors conclude that these results reflect "the necessary fallability inherent in medical practice under the specific circumstances that pertained at the times of the various studies". They, along with others, advance the concept of necessary fallability and medical uncertainty. Because of the nature of the interaction between human observations and the laws of natural science, there is an irreducible and unavoidable fallability in the diagnostic process.[5]

The second major problem with the validity of cause-of-death on death certificates has to do with the incompleteness of the information available at the time of death. The impact of clinical diagnostic uncertainty on the current health care marketplace can be seen in studies on the impact of autopsy data on DRG reimbursement (Table 5). In a retrospective review of 64 autopsied patients at the Mt. Sinai School of Medicine in New York, 20 (31%) had different principal diagnoses when medical record abstracts were compared with autopsy results.[6] Although the DRG classification changed in 12 of these 20 cases (60%), the potential reimbursement was not significantly changed. In a second study of 100 consecutive autopsied cases from the Veterans Administration Medical Center in Portland, Oregon, discrepancies between the clinical diagnosis and the diagnosis assigned following review of the autopsy findings resulted in 13 changed principal diagnoses.[7] For 12 of these 13, the DRG compensation would have increased; the hospital would have received an additional $14,235 had these diagnoses been used. The study concludes that it would be cost-effective to perform autopsies on specific groups of patients. Those with a high probability of a clinical-pathologic diagnostic discrepancy appear to be elderly patients whose hospital stay was relatively short, generally less than one week, who had multi-system disease, and who were unable to give an accurate clinical history. Finally, in 100 consecutive patients in whom autopsies had been performed at Michael Reese Hospital in Chicago, the principal clinical diagnosis was altered in 24% of deaths when autopsy findings were considered.[8] This would have resulted in a net increase of over $47,000 in the all-payor reimbursement to the hospital. Appropriate and optimal reimbursement was obtained by increasing diagnostic specificity or identifying clinical misdiagnosis.

These various studies all draw a similar conclusion — new and improved methods have not outmoded the autopsy as a means of confirming, clarifying, and correcting antemortem diagnoses. The autopsy can and should be seen as part of the solution to the problem of inadequate medical information at the time of death and potentially bears an important role in the future improvement of cause-of-death reporting.

Yet the autopsy has been in decline for over 40 years. Hospital autopsy rates have fallen from 50% in the mid-1940's to approximately 10% in the mid-1980's.[9] The autopsy has been referred to as a moribund art - near death itself.[10] Should the decline be applauded, ignored, or deplored? The decline should most surely be deplored. The consequences of the decline are several: clinicians' questions are not answered, misunderstandings are not corrected; an assessment of the accuracy of medical certification of death is more difficult; undiagnosed infectious diseases — tuberculosis, AIDS — may be missed or not accurately reported; accidental deaths and suicides may be undetected; new environmental hazards and iatrogenic diseases go unrecognized; the clinical training of medical studies and physicians is impaired; and finally, assessments of the quality of medical care are impaired as the autopsy continues to decline.

Who is it that undergoes autopsy? The proportion of all decedents who undergo autopsy is small; in Connecticut in 1979 and 1980, only 14% of all deaths were autopsied.[11] Individual hospital rates vary from a low of under 5% to over 40% with rates generally higher in teaching hospitals and larger hospitals. When studied by place of occurrence of death, 56% of deaths occur in hospitals but account for 77% of autopsies. 20% of all deaths occur in extended care facilities (nursing homes) and yet account for only 1% of all autopsies. The marked discrepancy and diminished interest in causes-of-death in the elderly is reflected in the age differences —only 2% of people over age 90 at death are autopsied.[12] There is a relatively constant increase in the numbers of deaths with increasing age, with the peak age specific death rate in the 80 to 84 year old age cohort. But the peak age specific autopsy rate —the proportion of deaths in an age group which undergo autopsy — is highest in the 20-29 year old age group -76%. This reflects increased traumatic deaths, particularly in young males. Although only 6% of deaths occur before age 35 years, these deaths yield 28% of all autopsies. Conversely, 60% of deaths occur after age 70 years, but these deaths account for only 7% of all autopsies. As the autopsy continues to decline, is this enough of a check for the health data needs of an aging population?

By cause-of-death, autopsy rates are much lower for some fatal conditions. Of the major categories of cause-of-death used in 1977 U.S. Mortality Statistics, disease-specific autopsy rates greater than 50% occurred with only six causes: homicide, abortion, other complications of pregnancy, meningococcal infections, bacterial dysentery, and other external causes. These six accounted for only 2% of all U.S. deaths. By contrast, the autopsy rate for cardiovascular deaths was 10% and for deaths due to cancer 11%.[9] Erroneous diagnosis as to cause-of-death is made almost twice as often in patients 70 years and older.[13] Ischemic heart disease and cerebral vascular accident, two of the major causes of death in the elderly, are often misdiagnosed. It is the prevalence itself of these diseases in later life that creates a bias against autopsies when these diseases are suspected — a common disease will, of course, be implicated more readily in a given set of circumstances and an autopsy deemed unnecessary. There are indeed compelling reasons to obtain more autopsies in the geriatric age group.

Two additional issues which bear on the validity of medical certification were mentioned at the outset — the various ways in which death certificates are completed and the classification of underlying cause in the vital records system. First, let us address the issue of death certificate completion. Physicians, to a large extent, shape the content of mortality statistics by what they write or do not write on the death certificate. Yet the majority of physicians have little awareness of what happens to the death certificates they complete, how the data is coded and tabulated, who NCHS is, and what the data is used for. The majority of physicians also have very little training in the "hows, whats and whys" of completing death certificates. A clear understanding, for example, of the differences between immediate and underlying causes is not prevalent.

This distinction lies at the heart of the final issue — the classification of cause in the vital records system. For many years, descriptions of cause-specific mortality data have been presented almost entirely in terms of a single underlying cause for each death. This characterization of mortality was probably adequate as long as the major public health problems involved acute infectious diseases. It has, however, become less appropriate as an increasing proportion of deaths have been the result of chronic disease. Deaths due to chronic diseases are often not well characterized by a single cause; rather they are more likely to represent a number of coexisting conditions among which there may be no direct etiologic chain to facilitate the identification of a single underlying cause. Multiple cause-of-death statistics can be valuable in the more accurate portrayal of mortality when deaths are attributable to a number of concurrent disease processes.[14] Although underlying cause is conceptually easy to understand, often it does not convey the complexity of the reported medical conditions at the time of death. Issues of validity and reliability, which have been discussed with regard to underlying cause, become even more important when statistical use is being made of all conditions that are listed on the death certificate.

What does all this data say? It says that the quality of the medical information on the death certificate is fundamental to our use and interpretation of mortality statistics. The measurement of accuracy of cause-of-death reporting is to some extent dependent on the analytic requirements of the data as determined by the data user. The epidemiologist has a need for highly accurate and sensitive medical information on individual patients. By contrast, the community health planner who is examining time trends in broad disease groupings has a need for consistency in aggregate data. Net gains and losses, which undermine the work of the epidemiologist, pose less of a problem for the planner as long as the discrepancies do not alter the rank order or proportion of cases in various disease categories.

Given the problems influencing the validity of cause-of-death — medical uncertainty, incompleteness of information, physician education, and the complexity of chronic dieases — as well as the aforementioned hypothesis that accuracy of medical certification can be improved, what can be done? I would like to suggest three areas for action. First, improvements in collection can be facilitated by continuing improvements in the death certificate form. Revisions in the U.S. Standard certificate, to be implemented in 1989, are a part of this. Second, and more important, is improving physician certifiers. Education of physicians as to what information is desired and how to record it will have more widely reaching consequences than any form changes could hope for.[15] Collaboration between NCHS, medical speciality societies, and graduate medical education associations should be directed toward improving death certification through physician education. Efforts should begin during medical school, with increasing attention during the years of postgraduate training — internship and residency.

Finally, because of the greater sensitivity and specificity of autopsy information, the autopsy can and should be part of the data base of mortality statistics. Individual death certificates are infrequently completed with the input of the autopsy. Even when autopsy information becomes available, death certificates are not frequently corrected. Except for periodic reviews, autopsy data is seldom aggregated. In 1982, NCHS reported, "apparently no country has a well-defined program for systematically assessing the quality of medical certifications being reported on death certificates or for measuring the error effects on the levels and trends of cause-of-death statistics."[2] In light of the need for quality assurance, the on-going collection of population-based autopsy data would be one means of addressing the issue of accuracy of causes-of-death. An on-going validation registry could be established in a manner analogous to the Surveillance, Epidemiology and End Results or SEER program for cancer statistics.[15,16] Autopsy information for well defined, sample, geographic and demographic areas would be continuously collected and linked to the death certificates for the same sample areas. The results of such a population-based validation registry could be used to make accurate extrapolations for the quality of all medical certifications, again analagous to the use of the SEER data with cancer. The epidemiologic use of necropsy information has been recently described.[18] The goal of such a program would be to improve health care through the aggregation of an existing sensitive and specific data source. Given the limits of medical certainty, the mutual supplementation of the death certificate and the autopsy could be considered to be the most valid estimate of the true cause-of-death.

TABLE 1
DIAGNOSTIC DISCREPANCIES IN THREE MEDICAL ERAS
CLINICAL DIAGNOSIS VERSUS AUTOPSY[4]

Discrepancy Level	1960	1970	1980
I. Missed Major Diagnosis, Clinical Impact	8%	12%	11%
II. Missed Major Diagnosis, No Change in Management	14%	11%	10%
Total	22%	23%	22%

TABLE 2
AGREEMENT ON UNDERLYING CAUSE OF DEATH
CLINICAL DIAGNOSIS VERSUS AUTOPSY, CONNECTICUT, 1980[3]

	Number	%
Exact Match	121	45
Intermediate Match	72	26
Major Disagreement	79	29
Total	272	100

TABLE 3
AGREEMENT ON UNDERLYING CAUSE OF DEATH FOR SELECTED DISEASES
Connecticut, 1980[3]

Category	Exact Match	Intermed. Match	Major Disagree.
	%	%	%
Neoplasm	66	21	13
Circulatory	44	38	18
Respiratory	0	33	67

TABLE 4
THE SENSITIVITY OF CLINICAL DIAGNOSIS VERSUS AUTOPSY FOR SELECTED DISEASES*

Disease	1930-39	1940-49	1959	1970-71	1975-77
Leukemia	90%	91%	93%	—	96%
Rheumatic Heart Disease	47%	—	51%	71%	71%
Pulmonary Tuberculosis	91%	88%	51%	—	50%
Peritonitis	61%	59%	—	—	48%
Carcinoma of the Liver	40%	17%	61%	—	28%
Cirrhosis	58%	64%	70%	75%	63%
Acute Myocardial Infarction	26%	79%	—	71%	80%

TABLE 5
THE IMPACT OF AUTOPSY DATA ON DRG REIMBURSEMENT

	No. of Autopsies	Different Principal Diagnosis	Net Change in Reimbursement
Mt. Sinai (1985)[6]	60	20(31%)	-$ 1,093
Portland VA (1986)[7]	100	13 (13%)	+$14,235
Michael Reese (1985)[8]	100	24 (24%)	+$47,408

Footnote

*Anderson RE, Hill RB, Key CR: The sensitivity and specificity of clinical diagnostics over five decades: Toward an understanding of fallibility. In press.

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Session M

Statistics for Health Planning for an Aging Society: The Report of the National Academy of Sciences

DATA FOR AN AGING POPULATION

OVERVIEW OF THE REPORT

Dorothy M. Gilford, National Research Council

Five years ago the National Academy of Sciences and the Institute of Medicine recognized that the aging of the population is a fundamental and far-reaching demographic shift that will have profound impact on society, the economy, and health care in the United States. This demographic trend has already generated public policy debates in health, welfare, medical care costs and financing, and other economic aspects of care. In order to identify some of the major policy issues related to an aging society, the National Academy of Sciences and the Institute of Medicine established a Committee on an Aging Society. Staff of the Committee on National Statistics who attended meetings on these policy issues raised questions about the adequacy of existing statistical information for policy development. The Academy therefore convened a conference to review the existing data related to health, housing, income and wealth, labor force participation, and retirement patterns of the elderly. Conferees identified numerous serious data gaps and agreed that a more careful review was needed.

THE STUDY AND THE PANEL ON STATISTICS FOR AN AGING POPULATION

The conference findings led to a study on Statistics for Policy Analysis for an Aging Population that was funded by a consortium of agencies including the Health Care Financing Administration, National Center for Health Statistics, National Institute on Aging, National Institute for Mental Health, Office of the Assistant Secretary for Planning and Evaluation of the Department of Health and Human Services, Social Security Administration, and Veterans Administration.

The contract called for the following three major activities:

1. identify data requirements for the next decade for policy development for health care for an aging society, assess the adequacy of current data sources, and recommend actions to remedy the shortcomings

2. determine the need for changes or refinements in the statistical methodology available for health policy analysis, program planning, and administration, and recommend actions or further research

3. recognizing that the federal statistical system in the United States is decentralized, identify the essential components of a comprehensive program of statistics to provide adequate data on aging for all policy areas, and recommend changes and procedures to facilitate integrating data from various components. This activity differs from the first two in that it is not limited to health policy but covers other sectors as well, such as labor force participation, housing, and income and wealth.

To guide the study, the Academy appointed a Panel on Statistics for an Aging Population, chaired by Sam Shapiro of Johns Hopkins University. The panel organized its work by establishing working groups on (a) health and related issues and associated data requirements, (b) statistical methodology for health policy analysis, and (c) improvement of data resources for policy analysis on aging chaired by panel members Dan G. Blazer,II, Gary G. Koch, and Dorothy P. Rice, respectively. Other panel members are Laurence G. Branch, Neal E. Cutler, Jeanne E. Griffith, Robert L. Kahn, Judith R. Lave, Kenneth G. Manton, John W. Rowe, Ethel Shanas, and James H. Ware.

PUBLICATIONS FROM EARLY PANEL ACTIVITIES

Before describing the organization and contents of the final report of the panel, I want to mention two other publications from the study: an "Inventory of Data Sets Related to the Health of the Elderly" that was published in connection with Senate hearings on "Statistical Policy for an Aging America" (U.S. Senate, 1986) and a volume of twelve papers commissioned by the panel as background for the study.

One of the early activities of the panel was to prepare an inventory of the existing data sets related to health of the elderly. Lillian Guralnick ably monitored the preparation of the inventory with help from representatives of the sponsoring agencies as well as many other individuals responsible for various data sets. To limit the inventory to a workable size the following criteria were established for inclusion of a data system in the inventory:

1. the data system includes a periodic or a continuous national collection of information related to the health of the elderly population of the United States

2. it contains one-time, or subnational studies, of seminal importance

3. it contains current data, or the most recent available data for a particular topic

4. it provides basic demographic data

and

the data set is available for further analysis even though there may be some restrictions on use of the data.

After considerable work, 117 data sets that met the criteria were identified. The inventory provides a 2-3 page summary for each data base that includes: a description of the data base; its purpose, design, and content; publications based on the data; information on the availability of unpublished data; the name and telephone number of a contact knowledgeable about the data base; detailed information about the types of data collected: and the size of the sample for age categories for age 65 and over. I am pleased to note that the National Center for Health Statistics has adopted the inventory format to describe the data sets in Health Statistics on an Aging Population (National Center for Health Statistics, 1987), which was distributed at this meeting.

Early in the study, the panel commissioned twelve papers as background for preparing the final report and formulating recommendations. The papers were presented at a symposium attended by representatives of agencies, Congressional staff, and members of the research community concerned with aging. The purpose of the symposium was to obtain input from policy makers and researchers concerning the major policy issues and data gaps related to those issues. The volume of papers will be published by the National Center for Health Statistics this fall.

CONTENTS OF THE PANEL'S REPORT

Summary and Recommendations The first chapter discusses the changing character of the agenda of specific policy issues for health care for the elderly. The difficulties inherent in predicting the specific policy issues that will arise during the next decade led the panel to identify seven broad policy areas and to determine the data requirements related to these areas. This chapter discusses a dozen high priority recommendations organized by these policy areas. These recommendations are followed by a section on the findings of the panel including five general recommendations that summarize the many detailed recommendations found in subsequent chapters. The full set of detailed recommendations is also presented in a table showing agencies that would have responsibility for implementing them. There are many recommendations, but they are addressed to 21 different agencies. Further, the panel recognizes that most of the agencies that produce data on the elderly also have responsibility for data for other subgroups of the population. The panel, therefore, envisions that the recommendations would be implemented over the next decade as they fit into agency plans. No major new data collections are recommended. The panel has instead recommended ways of augmenting and improving existing surveys and systems of administrative records--another reason for the large number of recommendations. The chapter concludes with a discussion of several important data bases that are outside the scope of this study. These include data bases resulting from epidemiologic studies, and international and sub-national data bases.

Social, Economic,and Demographic Changes Among the Aged The report devotes a chapter to the now familiar topic--the greying of the population--and discusses a variety of population forecasts for the aged. These trends and their interactions are the driving forces behind the concern about policy for the elderly. The chapter includes forecasts of the size of the future population of the aged showing the growing number of those over age 65 and especially the rapid growth of those of age 85 and over, the oldest-old. There are also forecasts by race and by sex. Since the ratio of men to women decreases with age and the total number of elderly is projected to increase there may be many elderly women living alone. Projections of the geographic distribution of the elderly show that there are differential rates of change by region. For example, while a 12 percent increase in the elderly by the year 2000 is projected for the northeast, an increase of over 60 percent is projected for the south and the west. These projections have obvious implications for medical care utilization and the need for nursing home beds for these regions. Projections by marital status and living arrangements show an increase in the number of women of age 65 and over who are living alone, with implications for need for social support and health services by the community or other public sources. The future elderly population is expected to be better educated than the present elderly and therefore can be expected to demand better health care. Projections of the sources of income and major expenditures of the elderly are provided, information that plays an important role in developing policy for federal support of programs for the elderly. The chapter discusses trends in labor force participation of the elderly. Since 1960 the percentage of men age 65 and over in the labor force has been declining, reaching 16.3 percent in 1984--a trend that has obvious implications for retirement programs and economic dependency of the elderly. Finally, future morbidity patterns are considered. As people live longer, will there be an increase in years with chronic disease or will there be a delay in the onset of disability with a compression of morbidity near the end of life? The report describes how these trends helped determine the topics selected for the next seven chapters of the report, which deals with data for health policy.

Data for Health Policy for an Aging Society Chapters 3-9 of the report provide the panel's findings and recommendations resulting from the first major activity of the study--identifying the data required for the next decade for policy development for health care for an aging society. The policy issue areas considered are health status and quality of life, health transitions and the compression of morbidity, health poromotion and disease prevention, quality of care, long-term care, the financing of health care services for the aged and health services for the aged. I will not elaborate further on these chapters since they are the topic of Dorothy Rice's paper, which is the next paper in this session.

Enhancement of Utility of Statistical Systems Chapter 10 responds to the third charge to the panel--to make recommendations that will facilitate use of multiple data bases for policy analysis for the aging population, not only for health policy but for other policy areas as well. Four categories of data are considered in this chapter: national data, federal-state data, private data bases, and quasi-academic organization's data.

National Data. This country has a large decentralized data system, at least 19 agencies produce data related to the aging population. Public policy for the elderly is being developed in a context of major changes that affect the demand for and the delivery of health services, as well as major changes in many other facets of policy that affect the lives of the elderly. Information is also needed to assess the effects of policy changes, otherwise policy will be made in a vacuum. Policy issues in one area, such as health, also call for an understanding of social, demographic, and economic characteristics and dynamics. Consequently, policy analysts need to draw on multiple data bases and coordination of data systems is required to make it feasible to analyze data from multiple sources. High priority should be given to issues of coordination, planning, and priority setting for data on aging. The need for such coordination was recognized by federal agencies in May 1986 when the National Institute on Aging and the Bureau of the Census cosponsored a Summit on Aging-Related Statistics for the purpose of determining how the federal statistical system can meet the data requirements for policy analysis for an aging society in a cost-efficient manner. The summit meeting led to the establishment of an Interagency Forum on Aging-Related Statistics for the coordination of federal statistical programs relating to aging. The report discusses the following six types of issues that should be considered:

content of surveys and administrative record systems--data producers frequently are not in close proximity to policy analysts and other data users

coverage, e.g. should the institutionalized population be included in surveys

data detail, especially for subgroups of the elderly as the total number of elderly increases

uniform definitions, concepts, classifications, e.g. for policy analysis, data for the same age categories should be available from all agencies

periodicity, consideration should be given to synchronizing surveys conducted by different agencies so that data are available for the same year, also survey cycles should be short enough to provide timely data for policy analysis

data access, e.g., provision should be made for public use tapes and access to microdata files at the time a data system is being planned.

This chapter also discusses the enhancement of three national surveys that are not major health surveys but are closely related to health of the elderly, viz., the American Housing Survey, the Retirememt History Survey, and the Survey of Income and Program Participation.

Federal-State Data. Joint efforts of the federal and state governments are required in the collection and preparation of data for monitoring social policies and programs. Vital statistics and data on mortality are collected by states but become part of a national data system. Disability statistics, on the other hand, are collected by the Bureau of the Census, but are used by numerous state and federal health and social service programs for resource allocation and monitoring programs. There is a growing need for age-detailed data and timely data at the sub-state level about the size and distribution of the elderly population for purposes such as budgeting for community health services, hospital beds, and nursing homes. Data on nutrition and social service programs that are implemented at state and local levels are also important at the national level since these programs are important factors in maintaining the health and independence of the elderly.

Private Data Bases. Although the panel makes no recommendations about private data bases, the panel reviewed these data bases to make certain that our recommendations would not lead to duplication. A discussion of these data bases is included in the report as a resource for the reader. Data bases described include data on hospitals collected by the American Hospital Association, data on nursing homes collected by the the Americal Health Care Association, data on health maintenance organizations maintained by the Group Health Association of America, data on hospices collected by the National Hospice Organization, data on commercial health insurance companies available from the Health Insurance Association of America, and data on health professionals collected by professional associations (American Medical Association, American Dental Association, and American Nurses Association).

Quasi-academic Organization's Data. Useful health policy data are available from a variey of private organizations doing health related research such as The Urban Institute, The Brookings Institution, and the Institute of Medicine.

Statistical Methodology for Health Policy Analysis The last chapter of the report describes the panel's findings and recommendations in response to the second charge to the panel and is the subject of the third paper in this session to be presented by Gary Koch.

In summary, this paper in combination with the other two papers of this session should provide a complete overview of the report of the Panel on Statistics for an Aging Population.

IMPROVEMENT OF DATA RESOURCES FOR POLICY ANALYSIS FOR AN AGING POPULATION

Dorothy P. Rice, University of California, San Francisco

The changing age structure of the population represents a most significant demographic change affecting American society. There is an urgent need to address a variety of policy issues related to the organization, delivery, and financing of our medical, social, and long-term care services to meet the needs of the growing elderly population. Adequate statistical information is needed to make health and related policy decisions for the elderly on a sound bases. My presentation summarizes the study of the Panel on Statistics for An Aging Population conducted under the auspices of the National Academy of Sciences. It will focus on:

1. The major policy arenas and issues relating to an aging population for which reliable and time data are needed to make rational decisions in a society with limited resources and many competing needs.

2. Within these policy areas, a brief review of the specific needs and gaps in policy relevant information for an aging population.

The Panel identified seven general health policy areas: quality of life, compression of morbidity, health promotion and disease prevention, quality of care, costs and financing of health services, use of medical services, and long-term care. The Panel carefully and systematically 1) identified the current available and planned data collection activities within each of these policy areas; and 2) identified data gaps and requirements for the collection and analysis of statistical data on the elderly population over the next decade.

Our report is comprehensive and lengthy. I can only touch on a few data requirements and gaps in each of these areas in the short time that I have.

Quality of Life

People are living longer but the important issue is the quality of the additional years of life for the elderly. Are the additional years ones of vigor and independence, or of frailty and dependence? The debate among health professionals has begun, but with a conspicuous lack of data in both sides.

Collection of appropriate and detailed data on quality of life and health status will become increasingly important over the next several decades. In choosing which data need to be collected and how they should be analyzed, it is essential to recognize that the needs of the elderly differ from those of younger individuals, both quantitatively and qualitatively. The elderly require special approaches and their health care needs reflect a complex interaction of physiologic changes with age, their psychosocial concomitants, and the various pathologic processes that occur with advancing frequency in senescence.

Contrary to popular belief, the elderly are highly diverse with respect to many characteristics, whether it be health or functional status, economic or social circumstances, or living arrangements. Frailty, ill health, and disability increase, on the average, with age, and data on these processes are needed. Many elderly persons, however, are in excellent health and function independently in most if not all areas of their lives. These persons often experience a high quality of life and engage in satisfying productive activity.

Maintaining and improving the quality of life of our fast-growing elderly population emphasize the need for maintaining functional capacity and increasing life expectancy.

Most of the well-known health status measures describe functional status along one of four dimensions: physical function, cognitive function, mental function, and social function.

All of these aspects of monitoring quality of life highlight a variety of data gaps:

1. New and better multidimensional measures of functional status need to be developed and incorporated into surveys of the elderly.

2. We need to be able to study the health status of the population by disaggregating data from surveys as well as from administrative records in 5-year age groups, beginning before age 65 to the very old age group.

3. Data collection also should take into account the positive aspects of aging rather than purely functional decline, disease, and mortality.

4. There needs to be increasing recognition of the capacity of individuals to improve over time; thus, data sets should be conceptualized with

a view to following individuals as they increase in their functioning, rather than necessarily entering a pathway of progressive loss of function leading to disability and ultimate mortality. This implies the need for longitudinal data, which was a recurring theme all through the deliberations of the Panel.

5. Productive activity, work that is performed and contributes to the economy paid or unpaid, should be measured and monitored.

6. Finally, the Panel recognized that for those older persons who reside in institutions such as nursing homes, the factors that contribute to satisfaction with life, a sense of well-being, and feelings of self-worth are somewhat different from those in the community and data are needed to fill this gap.

Compression of Morbidity

A major policy issue relates to the relationship between changes in the mortality experience of the elderly population and changes in their underlying morbidity and disability experiences. A controversy of major importance for health policy is whether future increases in longevity will be associated with prolongation of dependency or whether active life expectancy will increase as health promotion and disease prevention strategies become increasingly effective. The "comprehension of morbidity" theory or hypothesis advanced by Dr. James Fries of Stanford University is that as mortality rates decline morbidity rates will also decline and people will live in a healthy state until old age when they will die of natural causes. This theory has recently been challenged by studies suggesting that the increased life span of the "old-old" is not accompanied by decreased morbidity and may actually result in more dramatic increases in the need for health care services. While federal statistics have documented the changes in mortality and life expectancy during the twentieth century, there are no national data showing whether the period of vitality has also changed. Thus, we do not know whether either the actual number or the proportion of the later years spent in a healthy state has increased.

Basic requirements for measuring morbidity changes are data for health transitions. In assessing health transitions in old and very old populations, a number of conceptual, measurement, and analytic issues emerge that are not as evident in younger populations.

Health transitions at later ages cannot be simply described in terms of the incidence rate of independent disease events. Instead they must be viewed in terms of multiple, interacting disease processes that operate in a host with generally declining homeostatic reserve. These concepts involve modeling health changes in the elderly person as changes in a complex multi-dimensional system evolving over a considerable period of time. In order to describe health transitions at advanced ages, certain types of new data are needed and development of new methodologies for analyzing longitudinal data is required.

1. Long term follow-up of well-characterized cohorts. Again longitudinal data are needed. In order to describe health transitions among the elderly, repeated measurements are needed of physiological, social, and health characteristics to better understand the age dynamics of physiological risk factors at advanced age.

2. Determination of morbidity and mortality risks among nationally representative samples of already morbid and disabled persons. This would help us resolve some of the questions about the societal impact of life expectancy gains at later age. The prevalence of many chronic diseases is too low to permit the analysis of morbidity and mortality risks for morbid sub-populations using general health surveys. Adequate samples of morbid sub-populations are required.

3. Systematic extension data collection for clinical studies to measure co-morbidities. Not only is the issue of co-morbidity important for describing "normal" aging changes, but it is important for determining appropriate clinical responses to disease at advanced age. Currently most clinical data bases do not collect extensive data on co-morbid conditions.

4. Data that relate chronic disease diagnosis to level and type of disability. This would enable us to utilize the extensive epidemiological data on disease risk factor associations in forecasting future demand for long-term care services.

5. More spatially disaggregated data. Geographic disaggregation would allow us to take better advantage of naturally occurring population differences in risk. Different subpopulations have very different exposures and disease risks.

Health Promotion and Disease Prevention

The Panel was aware of the inconclusiveness of efficacy of some prevention strategies for the elderly. Nevertheless, there are several reasons for adopting a health promotion/disease prevention approach for the elderly, despite legitimate cautions. Among them are the plasticity of the aging process; the possibility of modifying physiologic or pathologic conditions which, although associated with so-called "normal aging" also entail risks to health; and the high incidence of chronic disease among the elderly. In addition,life expectancy is increasing and it is desirable to enhance health status and quality of life during these additional years of life.

Despite the obvious importance of health maintenance/disease prevention, data are not routinely available through national data systems on the extent to which the population is informed as to the causes of "preventable" illnesses and conditions and the actions they as individuals might take to reduce their own risks of developing such illnesses and accompanying impairments.

The Panel sees a need for separate health promotion/disease prevention modules to be incorporated in surveys that are appropriate to the elderly and subgroups of this population, since risk factors and expected health and functional outcomes for particular diseases and diseases disabilities among the elderly vary. These modules range from breast self-examination and screening to role of diet, nutrition, and exercise, and others.

Health providers can play an important role in this area. A major drawback to fully exploiting the potential influence of physicians in health promotion/disease prevention among their patients has been the absence of data on the extent to which physicians currently engage in primary, secondary, and tertiary prevention activities with their patients.

Finally, comprehensive information on the numbers of professionals and allied health personnel who provide health promotion and disease prevention services to the elderly in a variety of settings does not exist.

Quality of Care

National data systems have been a largely underdeveloped source of information for measuring quality of care among the aged. There are compelling reasons for identifying needs for this type of information and the extent to which such systems could meet them. The Office of Technology Assessment in a recent report points out that "Medicare's propsective payment system (PPS) has intensified concern with the complex relationship between cost and quality of medical care" and "assessing PPS impacts on quality of care is critical...." Among the reasons given is that if PPS succeeds as a cost containment strategy, "its effect on the quality of care will be a deciding factor in the program's continual survival." In another report, the Institute of Medicine focused attention on the importance of information systems for assessing and improving quality of care of nursing home residents.

National data systems have the capacity to produce information needed to derive quality of care measures to determine how quality varies within the population, and how it may be influenced by sources of care and policies that affect services received. Many of the specific items required are included in surveys that are already operational or about to start; others are dependent on the extension of existing items or the introduction of new ones.

But additional efforts will be needed to develop and test new measures of outcome and processes of care, as well as methods for making reliable and valid observations on the aged who are well and those who are infirm or cognitively impaired. A significant expansion in the measurement of quality of care can be achieved through the use of presently available or readily adaptable measures, linkage of multiple data sets, and longitudinal information systems.

Costs and Financing of Health Services

For the aging population, the major policy issue that will confront the Nation during the next decade is the cost of supplying health care to the elderly to enhance their quality of life, who will pay for that care, and how.

The latest data recently released by HCFA show that the the nation spent $458 billion or 10.9 percent of the GNP for all health care in 1986. Medicare which provides health care for 32 million elderly and disabled contributed 19 percent of all personal health care spending.

With the growing number of elderly who are at risk for illnesses requiring medical care, spending for their health care will increase substantially. Several years ago, Jacob Feldman and I projected the impact of an aging population. We found that in 1980, the elderly comprised 11% of the population and they consumed 31% of all expenditures; by 2040 the elderly will comprise 21 percent of the population and will consume almost half the health expenditures.

Many types of data are required to provide a factual basis for policy needs related to the costs and financing of health care services for an aging population, including person-based survey data, administrative record data, and actuarial data.

Survey data should include information on health status, income, assets, medical care expenditures and sources of payment for medical care. Data need to be sufficiently detailed so that reliable statistics can be created for the most vulnerable of the elderly -- the frail, low income and minority groups. We need this information for people living in the community and in the institutions.

Additional data that are useful in the analysis of financing medical care services are the administrative records of HCFA, SSA, and IRS. Current constraints impede the usefulness of these data for policy purposes.

Actuarial data from private insurers are also needed. A complicating factor is that private insurers are reluctant to share their limited data bases to enable the development and marketing of long-term care insurance.

National health expenditure data for the elderly are widely used by policy makers to evaluate the adequacy of existing public programs in covering the health care costs of the aged population. The expenditure data also serve as a basis for assessing the possible consequences of changes in public policy and programs. The Health Care Financing Administration (HCFA) periodically publishes data on health care expenditures of the population aged 65 and over by type of expenditure and source of funds as part of the national health expenditure accounts for the entire population that are published annually by HCFA.

A major gap is the absence of these aggregate expenditures data of the aged population by source of funds and type of expenditures on a timely and a regular basis.

One of the major sources of data on health financing are the national expenditure surveys. The current 1987 National Medical Expenditure Survey (NMES) follows a series of national medical expenditures surveys, including the 1980 National Medical Care Utilization and Expenditures Survey (NMCUES) and the 1977 National Medical Care Expenditures Survey (NMCES). While the data sets from these surveys have served health care policy makers and analysts well, they will be long out of date by 1988 or 1989, when the first analyses from NMES data will be available. We do need periodic and regular collection of medical care expenditures through national surveys.

Cost-of-illness data play an important role in decision making regarding the allocation of resources in the health sector. Illnesses, such as Alzheimer's disease, that primarily affect the elderly will require more resources in the future with the growing number of elderly persons who may be at risk. The direct and indirect costs of these conditions are needed by policy makers, health planners, and researchers to set priorities, make program policy decisions, prepare and deliver Congressional testimony and support program agency budgets.

Use of Medical Services

The amount and types of health care services used by older adults are influenced by many factors related to health status, level of impairment or disability, as well as many factors unrelated to health needs *per se*. Among these are public policies that specify the types of services and providers covered by public funds, cost-sharing provisions, and deductibles; the supply of alternative sources and types of care; living arrangements and access to informal care; the availability of adequate numbers of trained personnel; advances or changes in health care technology and delivery systems; and the attitudes and values of potential recipients and providers of care.

Data gaps in use of medical care services include:

1. Disaggregated data for subpopulation groups including minorities, groups, poor and near poor

2. Data related to health manpower trained to work with the elderly

Comprehensive data on the numbers of professionals and allied health personnel who presently render direct care to the elderly do not exist. Nor is there information on the numbers of such personnel that will be needed in the future to meet the health needs of the rapidly growing elderly population.

3. Data to the measure the effects of changes in the organization, provision, and coverage of health care services

The health care financing and delivery system is undergoing rapid and profound changes. The adoption of DRGs and other prospective payment systems for hospital care, the growth of for-profit health care, the adoption of market-oriented approaches by health care providers, and the growth of competition in the medical care market may contribute to an unintended increase in the barriers to access to health care for our neediest citizens, many of whom are old.

Such changes in the organization and provision of health care and related services are having and will continue to have a considerable impact on the service utilization patterns not only of the general population but of the elderly as well. Provision must be made to monitor their impact over time through various continuing and periodic surveys, both provider a population-based.

4. Data on equity in access to care

Access to health care is a complex, multidimensional concept that can be applied to whole populations, population segments, or individuals. A number of national population-based surveys contain items designed to tap access to care.

The elderly, or segments of the elderly population, may experience special or different problems or barriers in securing access to care than the remainder of the population. Not enough is presently known about the factors that affect utilization of health services by the elderly and about the access barriers experienced or perceived by older persons.

Minorities and the poor elderly are likely to differ from the remainder of the elderly population in health status and other characteristics. These subgroups of the elderly population should be carefully monitored, and oversampled in surveys, for their health status and health-related service utilization because of their particular vulnerability and potential difficulties in obtaining access to care.

Long Term Care

Policy issues in long-term care focus on four major themes: the need for and use of long-term care; the determinants of such use; measures of need; and financing and reimbursement for long-term care.

Data gaps in long-term care include:

1. Common definition of long-term care

A major problem in assessing the magnitude of long-term care services and costs results from the lack of a common definition of long-term care in data collection and analysis, which is essential to policy analysis. The ideal record system for long-term care should be capable of monitoring all necessary data on the person throughout the course of his illness regardless of where his care is received.

2. Uniform or standard data

Long-term care services include a broad continuum of health care, social services, and residential care. These services are provided in settings that are either institution or community-based. All of these service providers collect some statistical data for administrative bodies -- federal, state, and local. The collection of uniform or standard data relating to long-term care by service agencies would yield comparable information on providers of care, services given, and the characteristics of the long-term care population.

A standard classification of the types of care given by long-term providers is essential. Only in this way can data be made available to evaluate the quality and effectiveness of services provided in different environments and by various health care professionals.

Standard definitions of informal and formal support are also needed. Definitions of informal support need to distinguish between support given by family members both in and out of the household, and by household members whether or not relatives of the recipient. The lack of clear definitions in this area creates ambiguities and leads to misinterpretation of data.

3. Expenditure data on long-term care

With the projected growth of the older population, and particularly of the very old, the demand for long-term care may be expected to increase. National expenditures for long-term care will also increase. Most of the national expenditures for long-term care are for nursing home or institutional care, although expenditures for noninstitutional care also have increased rapidly.

Much of the spending for long-term care services for the elderly are not reported in the National Health Accounts. Among such services are the costs of social services funded by states through Social Service block grants, and services funded through the Older Americans Act and other federal programs. The 1987 National Medical Expenditure Survey is collecting information on health status of individuals, their medical cost expenditures, and the source of payment for the civilian population as well as for the population in nursing homes, psychiatric hospitals, and facilities for the mentally retarded. The aggregation of these data from both households and institutions will provide an overview of expenditures for long-term care. These data, together with the data reported under public programs, will provide a basis for the development of an ongoing series on expenditures for long-term care and these need to be aggregated and published on regular and timely basis.

Conclusion

The report of the Panel on Statistics for An Aging Population contains many significant recommendations that will affect all of the Federal agencies that collect statistics on the elderly population. To adequately address the policy issues related to the organization, delivery, and financing of our medical, social, and long-term care services to meet the needs of the growing elderly population, the Federal agencies will need to carefully review their current data collection activities, make appropriate changes, and coordinate their efforts to enable the production of policy-relevant data in the most cost-effective and cost-efficient manner.

AREAS FOR RECOMMENDATIONS ON STATISTICAL METHODOLOGY IN HEALTH PLANNING FOR AN AGING POPULATION

Gary G. Koch, University of North Carolina at Chapel Hill

Abstract

Statistical methodology provides ways for understanding the information in data. Over the next several years, it must serve a major role for the delineation of issues relevant for an aging population. Two general areas of concern are the description of patterns of change of individuals and forecasts of status and needs for populations. One area of difficulty for these statistical activities is that no single data base is sufficient either currently or probably in the future. Another is the extent of uncertainty in data bases from sources of bias, measurement error, and sampling error. More specific discussion along these lines suggests areas for recommendations on statistical methodology.

1. Introduction

Health planning for an aging population requires data concerning aspects of health status, data concerning aspects of health care services, and data concerning patterns of change in health status and needs for health care services and other resources. Statistical methodology is also required to enable appropriate understanding of the information in such data as well as in other relevant data. The importance of statistical methodology is a consequence of the major roles which it must serve. Four roles which merit particular attention are as follows:

1. Description of patterns of change of individuals over time through the design and analysis of longitudinal studies.

2. Evaluation of the relationship between characteristics in different data bases through linkage procedures.

3. Forecasting future status and needs of the population of older persons.

4. Quantitative expression of uncertainty in statistical results due to sampling error, measurement error, and sources of bias in ways which suitably account for the nature of assumptions and the structure of information sources.

2. Longitudinal studies

Aging is a process which occurs for individuals over time. Individuals can experience improvement as well as decline. Also, such change not only applies to health status, but to economic status, social interactions and other aspects of life. The evaluation of change over time for individuals requires methods which are capable of measuring change and analyzing its relationships to other characteristics. These methods must involve the observation of each individual in a representative group at two or more time points; and so they must be based on prospective longitudinal studies. Through the identification of the correlates of change, longitudinal studies can be an effective guide for health policy. More specifically, they can enable evaluation of whether individuals with certain health status or lifestyle characteristics tend to have more favorable experience over time than other individuals. Such information from prospective longitudinal studies has substantial importance for the development of programs for an aging population by accounting for the heterogeneity of change for its individuals, e.g., programs to enhance the likelihood of favorable aging for as many individuals as possible on the one hand and to provide appropriate resources to those who experience decline on the other. Health policy could not be guided by appropriate considerations concerning heterogeneity of change if longitudinal data were not available.

Another reason why the evaluation of changes over time requires longitudinal studies is that other types of studies which might be used for this purpose have contraindicating limitations. For retrospective studies in which historical information at previous times is to be reported by individuals, one of these limitations is incorrect or incomplete information due to potentially substantial recall errors. Also, selective mortality can cause conclusions concerning change to apply only to the individuals who survived the time period over which the change took place as opposed to all individuals who were alive when it began. The factors which can mislead the description that a cross-sectional study provides for variation across ages include cohort effects and selective mortality. Successive cross-sectional studies enable cohort effects to be taken into account, but still can have important limitations from selective mortality.

There are several considerations which underlie the design of longitudinal studies. One of these is the unit of study; it can be a person in a family or all persons in a family with age in a qualifying range. The method used to select units for inclusion in a study is a second component of the design. It can specify all eligible individuals in a community or a random sample of individuals from a specified population. Other components of the design of longitudinal studies include the duration of the study, the number of time points at which individuals are observed, and the lengths of the time intervals between these time points.

Since longitudinal studies encompass the time period for their duration, several types of formidable methodological issues can require attention in their analysis and interpretation.

These include the occurrence of critical events like major illnesses or changes in lifestyle between times of observation rather than at them, study discontinuation by individuals at varying times for relevant (e.g., death) or non-relevant (e.g., disinterest in study) reasons, and missing data for one or more characteristics at one or more observation times. General statistical analysis strategies which can be useful for dealing with the previously stated issues and other aspects of data structure for longitudinal studies include multivariate linear models and stochastic process models. A stepwise approach involving model fitting is advisable for the application of such methods in order to account for potential difficulties from limitations of data or departures from model assumptions.

For additional discussion concerning statistical aspects of longitudinal studies, see Cook and Ware, (1983), Manton and Woodbury, (1983), Heckman and Singer (1985), Ware (1985), and Fienberg and Tanur (1986).

3. Record linkage

A major statistical problem in the usage of data in health planning for an aging population is that no single data base is sufficient. For example, some data bases pertain primarily to health status while others pertain primarily to utilization and costs of health services. Also, information concerning aspects of employment, housing, life style, and social interactions may be mostly provided by one or more additional data bases. Thus, linkage of data bases is necessary to enhance the scope of available data.

The linkage of two or more data bases can be at the aggregate or individual level. At the individual level, the match can be either exact or statistical. Three examples of exact record linkage are as follows:

i. Administrative data on retirement benefits to survey data in the Social Security Administrations Retirement History Survey (Fox, 1979).

ii. Survey records from the Current Population Survey, the National Health Interview Survey, and the National Health and Nutrition Examination Survey to death records in the National Death Index (Patterson and Bilgrad, 1985).

iii. Survey records from the National Medical Care Utilization and Expenditure Survey to records in the Medicare and Medicaid administrative data files (Cox and Bonham, 1983).

There are several methodological difficulties which the application of record linkage needs to address effectively. One of these is how the quality and extent of information for matching influences the extent of matching errors in linked data bases. Another is concerned with the implications of matching errors to the capability of analysis of linked data bases to provide sound conclusions. Additional factors which influence methodology for record linkage include resources for implementation, ethical and legal considerations, and concerns about public cooperation. For all of these, a focus of attention is the appropriate management of individually identifiable data by the federal agencies which are involved in record linkage projects. Also, a critical issue for the dissemination of linked data bases of individual records for public use is the risk of disclosure of information which identifies one or more individuals. A dilemma here is that the risk of such disclosure tends to increase as the scope of the linked data base becomes more extensive and thereby more useful for statistical analyses. For this reason, procedures for addressing the issue of disclosure in linked data bases will require careful consideration. Additional discussion of methodological aspects of record linkage is given in Jabine (1985) and Scheuren (1985).

4. Forecasting

There are several methods of forecasting characteristics and needs of an aging population. Some involve projections such as those from census data for population composition for age, race, and sex. The scope of projections by federal agencies also includes mortality, health services utilization, and health care expenditures (see Myers, 1985). For forecasts like those described here, structure is an important consideration. Some of its components are the regularity of production, the periods covered, and whether the format is based on a set of tables or files from a computer system.

Another strategy for forecasting involves models which seek to account for multiple factors which might interact with one another. Some models such as the Macroeconomic-Demographic Model (National Institute of Aging, 1984) have an aggregate structure. Alternatively, micro-simulation models deal with a created population of individuals who are at risk for a variety of experiences as they are aged over time. Finally, comprehensive and biomedically realistic stochastic process models can be mathematically postulated and then evaluated in terms of their applicability to existing or future data.

Several issues will make forecasting difficult for an aging population. Future cohorts of persons with age $\geq$ 65 years will be different from current ones in terms of education, life style, and health history. Also, for older persons, there are relatively high transition rates between states for well-being and those for illness or some other condition that may involve utilization of health or special services. Other factors which can influence the accuracy of forecasts are the quality of the data on which they are based and the appropriateness of the assumptions which are involved. In this regard, aspects of data quality include errors in reporting, non-response, and sampling variability when there is insufficient sample size for the age ranges being covered. An overall consideration for both data quality and assumptions is the sensitivity of projections; i.e., do projections change substantially if they are based on reasonable modifications of available data or assumptions. Such sensitivity may have considerable importance in the use of forecasts for health planning. For additional discussion of forecasting for an aging population, see Myers (1985).

5. Accounting for uncertainty

The usage of statistical methodology to address questions of health policy will need to account for the applicable sources of uncertainty. As noted previously, the nature of assumptions and data quality can influence forecasts. One way to describe uncertainty from this is through sensitivity analyses which seek to produce low, middle, and high values. Other statistical activities which can involve various sources of uncertainty are the integration of data from multiple sources and the incorporation of information which is supplemental to data and may be conceptual in evaluation processes. Additional discussion of issues concerning uncertainty in policy oriented analyses is given in Stoto (1985).

6. Areas for recommendations

Relative to the previous discussion, the following areas of statistical methodology merit recommendations which can enhance capabilities for health planning for an aging population.

1. Methodological research to strengthen the design and analysis procedures for longitudinal studies.

2. Linkage of data bases from surveys and administrative records which pertain to an aging population.

3. Forecasting in ways which account for issues of population structure and change for an aging population.

4. Ways of dealing with sources of uncertainty in the roles that statistical methodology plays in health policy.

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Session N

Role of Vital Statistics in Public Policymaking

DATA FOR AN AGING POPULATION

THE USE OF COMPUTERIZED VITAL RECORDS AS AN AID IN DETERMINING COMMUNITY PUBLIC HEALTH POLICIES

Neil M. Casey, Akron City Health Dept.

It is my opinion that the area of Public Health Statistics of the moderate to large city size is prime for a metamorphosis from the analysis of health trends in the overall population form to that of sub-population detail analysis. The reasons behind this opinion are:

1. Sub-populations within a community tend to congregate in the same neighborhood, overall community statistics would possibly not pick up an anomalous health event taking place in one specific sub-population.
2. The overall trends in the community may be very encouraging from the Public Health point of view, but one or two sections of the community may not be sharing in that good fortune.
3. From a Public Health policy viewpoint, the availability of small area statistics would afford Public Health officials the opportunity to have a firmer grasp of the total community's health needs, and target needed specific Public Health activities for needed areas.

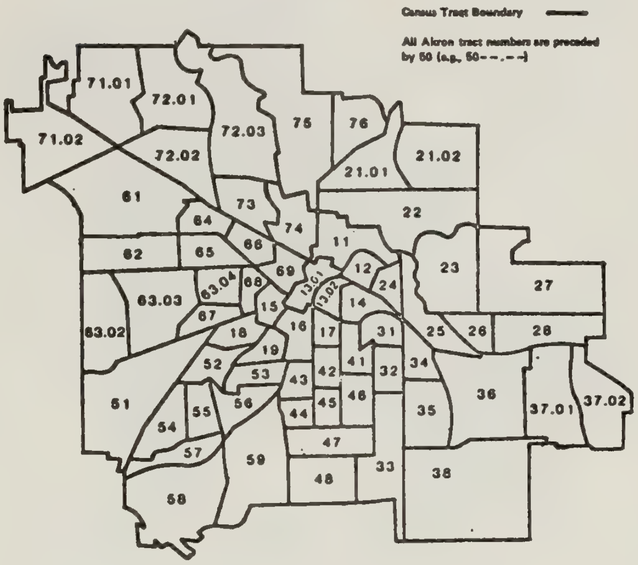
Reason 3 above can be stated as being somewhat analogous to a physician treating a patient, the doctor needs to have an overall view of his/her patient's general state of health, but by the same token will target specific remedies for the ailing parts of the patient's body while not causing any deterioration of the patient's overall health or to any other specific area of the patient's body. We in the Akron City Health Department consider the City of Akron as our overall patient, with the census tracts in the city as the individual body parts. (figure 1)

The Akron City Health Department began in 1980 geocoding the Census Tract information onto all Akron resident birth and death records which came into that office. At the same time the Ohio Department of Health's (ODH) Division of Vital Statistics, supplied by us with the necessary code books, began geocoding the Akron resident birth and death records which came to their office from local vital records other than Akron's. Usually, some time during the summer, the previous years vital records statistical tapes are ready and for sale by ODH.

The city data is immediately generated upon receipt of the tapes to ascertain if any anomalous blips in the overall trends have occurred. If their are any, the City Health Director is informed and then supplied with whatever additional information which he may require. If nothing untoward is found, the process of analyzing various aspects of the vital records data is begun.

FIGURE 1

CENSUS TRACTS FOR AKRON, OHIO, 1980



Prepared by the Lab for Cartographic & Spatial Analysis. The University of Akron.

Two points to be made here are: 1) This form of detailed geocoding was only begun in 1980, thus not enough data is available to accurately access detailed trends, and 2) The absolute numbers in some census tracts are so small that in order to have some statistical faith in the analysis, three years (or more) worth of data, in this case the years 1980-1982, are needed to acquire sufficient numbers. The balance of this paper will briefly document some of the analyses performed on this data, first on information on the birth records, then on data supplied on death records.

Birth Data

The statistical data available from the birth tape is voluminous and is shown in Table 1. As can be seen from this table there is a wealth of available information just by item but when one considers the crosstabulational opportunities, the amount of information becomes a deluge. For purposes of brevity, this discussion will be limited to crosstabulation of Census Tract with: 1) Trimester prenatal care began, 2) Prematurity as defined by birthweight, 3) legitimacy and 4) percent of Census Tract births to teen-agers.

Trimester prenatal care began

One sure way for a woman to help herself to a healthy pregnancy and a positive birth outcome is to begin prenatal care as early in pregnancy as possible, with the Public Health goal being that all women beginning prenatal care during the first trimester. Figure 2 shows the spatial distribution of the percent of women beginning prenatal care

TABLE 1

INFORMATION AVAILABLE FROM BIRTH STATISTICS FILE

DATE OF BIRTH
PLACE OF BIRTH
HOSPITAL OF BIRTH
RESIDENCE OF MOTHER
CENSUS TRACT
SEX OF CHILD
PLURAL BIRTHS
MOTHER'S AGE
MOTHER's RACE
MOTHER'S EDUCATION
FATHER'S AGE
FATHER'S RACE
FATHER'S EDUCATION
RACE OF CHILD
DATE OF LAST MENSES
MONTH PRENATAL CARE BEGAN
SEROLOGIC TEST
NUMBER OF CHILDREN NOW LIVING
NUMBER OF CHILDREN NOW DEAD
TERMINATIONS 20 WEEKS OR MORE
DATE OF LAST LIVE BIRTH
DATE OF LAST FETAL DEATH

LEGITIMACY
WEIGHT AT BIRTH
COMPLICATIONS RELATED TO PREGNANCY
COMPLICATIONS NOT RELATED TO PREG.
COMPLICATIONS OF LABOR
CONGENITAL MALFORMATIONS
EYE PROPHYLACTIC USED
ORIGIN DESCENT OF MOTHER
ORIGIN DESCENT OF FATHER
APGAR SCORE - 1 MINUTE
APGAR SCORE - 5 MINUTES
TOTAL PRENATAL VISITS
GESTATION IN WEEKS
TERMINATIONS PRIOR TO 20 WEEKS
ATTENDANT AT BIRTH

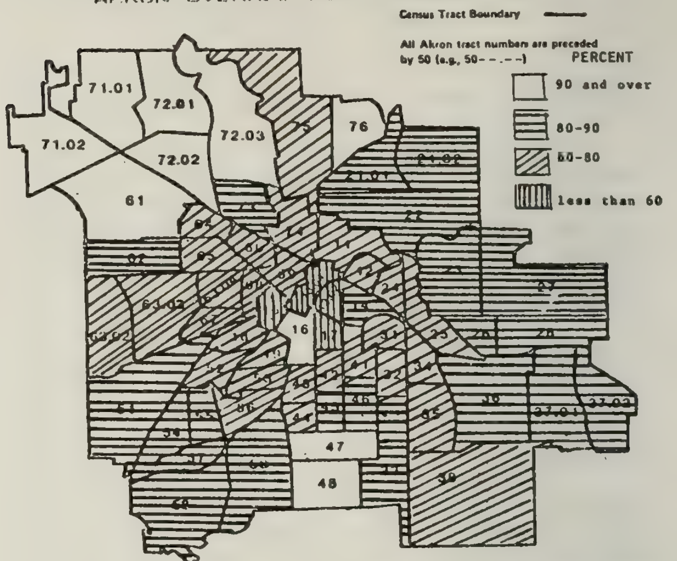
during the first trimester for each census tract. The 1990 objective for the nation is that at least 90 percent of pregnant women begin prenatal care during the first trimester[1]. As you can see from this figure the city as a whole is well on its way to meeting that goal with 81 percent seeking care during the first trimester. Some segments are in good shape with at least 90 percent of the women receiving some form of prenatal care within the the first three months. However, some sections are in poor shape with less than half the women receiving prenatal care during this critical period, and sizable areas with less than 80 percent of the women receiving prenatal care during the first trimester. If one were to look at a socioeconomic composition map of Akron, one would find that these areas correspond to areas of lower socioeconomic status.

The Public Health priority would be to target the less than 60 percent areas for immediate action, via health education and availability of health clinics and once these areas were brought up to a higher percentage, continue to progress here but also begin the process in the 60-90 percent areas, with the overall goal of bringing all sub-sections of the city to over 80 percent.

Prematurity as defined by birthweight

A premature birth as defined by birthweight, also called low birthweight, is any baby born with a birthweight under 2500 grams (5.5 pounds). The present percentage of births in Akron which are low birthweight is 8.9 percent. The 1990 objective for the nation is 6 percent[2]. It should be noted that the 1990 objective says that the 6 percent

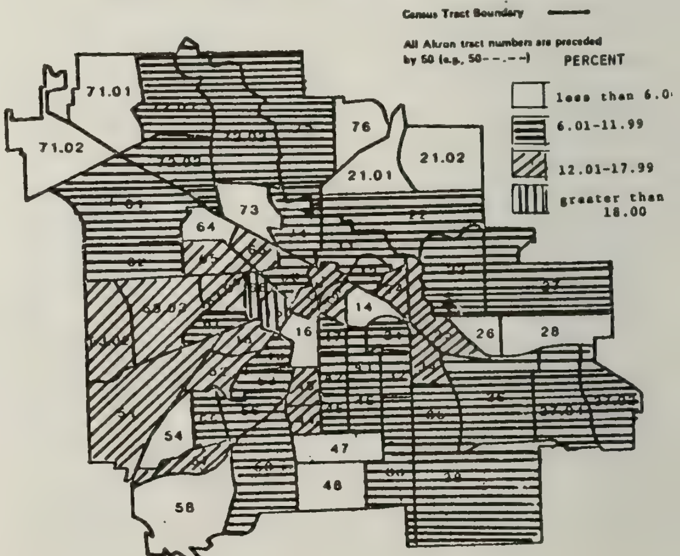
FIGURE 2
PERCENTAGE OF WOMEN BEGINNING PRENATAL CARE DURING THE FIRST TRIMESTER
AKRON OVERALL PERCENTAGE: 81.7



benchmark is the objective not only for the whole city but also for each "subgroup of the population a defined socioeconomic, ethnic, and geographic characteristics"[3]. For Akron these three characteristics are for the most part all correlated to the geographic location.

Figure 3 shows that Akron does not meet the U.S. objective as a whole. Some subsections of the city do meet the objectives while others fall way short. The pattern of low birthweight is roughly the same as for the previously discussed trimester prenatal care began. A prudent Public Health program could be developed to take advantage of this high correlation and thus improve both health indices simultaneously, at a more reasonable cost than attacking both problems separately.

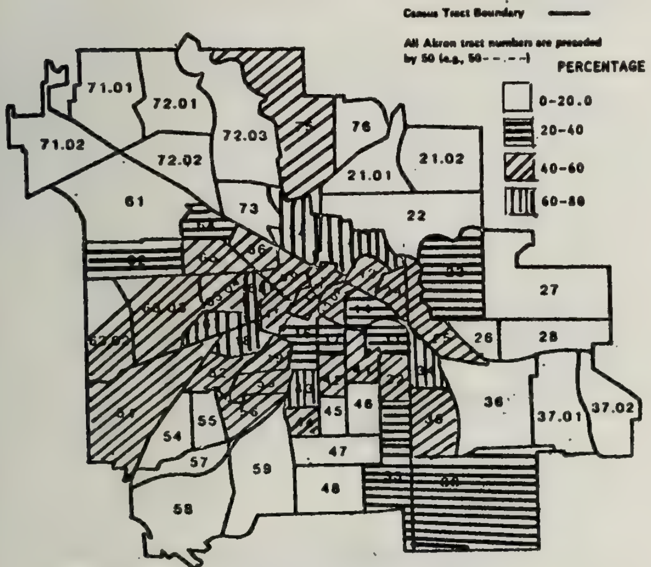
FIGURE 3
PERCENTAGE OF LOW BIRTHWEIGHT BABIES
AKRON OVERALL PERCENTAGE: 8.9



Legitimacy

It can be safely assumed that most illegitimate births are unintended, but for any number of reasons was not aborted. These women generally need special help in infant care, and making the personal adjustment to properly raise their child. Over 30 percent of the births in Akron during this time period were illegitimate. This fact shows up clearly in Figure 4 and shows the geographic distribution of this phenomenon. Again, it shows the same general pattern as the one previously noted. It appears here that sex education and counseling is especially needed in the areas with the highest percent illegitimacy and radiating out from there.

FIGURE 4
PERCENTAGE OF ILLEGITIMATE BIRTHS
AKRON OVERALL PERCENTAGE: 30.3



Teen-Age pregnancies

Closely allied to all of the above problems is that of teen-age pregnancies. Teens have the highest illegitimacy rate, tend to procrastinate in seeking prenatal care, and have a higher percentage of low birthweight babies. Teen-Age women account for 17 percent of Akron resident births. The percentage distribution by census tract is presented in Figure 5. Again, the pattern fits, north center, down through the center of the City, then off to the West and Southeast, with the more affluent sections of town being, in relative terms, healthy neighborhoods for positive birth outcomes.

Final comments regarding birth data

It becomes clear from this data that sex education at an early age, definitely preteens, is in order. This along with adequate prenatal care and counseling being readily available are necessary first in the central core of the City and then spreading out to the North, West, and Southeast (Figure 6).

FIGURE 5
PERCENTAGE OF BIRTHS TO TEENAGE WOMEN
AKRON OVERALL PERCENTAGE: 17.0

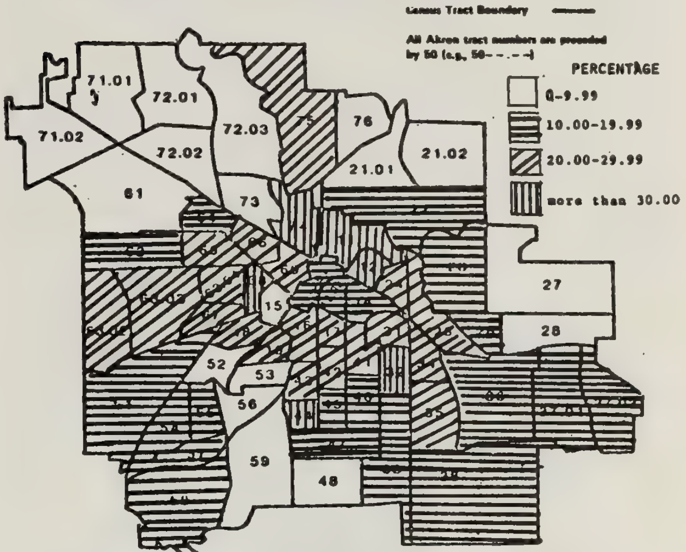
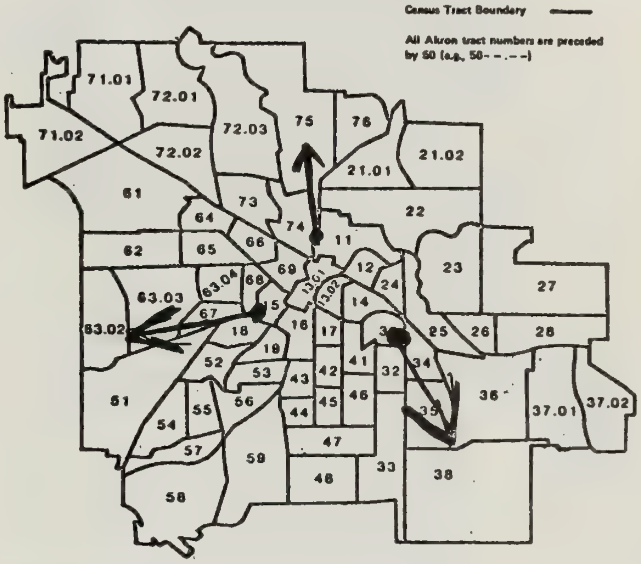


FIGURE 6
DIRECTION FOR OPTIMUM ALLOCATION OF PUBLIC HEALTH FUNDS TO PROMOTE A POSITIVE BIRTH OUTCOME



Death Data

Unlike the births, the objectives for the nation do not directly address an overall optimum death rate for specific causes. It does address factors which lead to premature death. The amount of data provided on death certificates is not as copious as on birth certificates, but enough is available to make some comparisons between the U.S., Akron, and the individual census tracts. Again, as before, three years of data were combined in order to assure an adequate number of deaths per census tract to make the analysis statistically meaningful. After grouping all the deaths, it became obvious that sufficient deaths occurred for only two specific causes. Thus this discussion will be limited to: 1) Total Deaths, 2) Deaths due to Heart Disease, and 3) Deaths due to Malignant Neoplasms.

Total Deaths

Figure 7 displays crude death rate for the census tracts in Akron. For comparison purposes the U.S. Death Rate for 1981 is also presented.

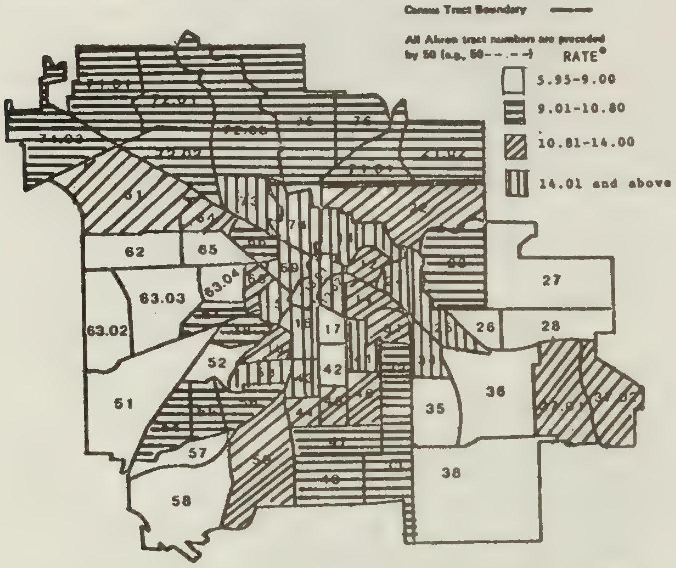
FIGURE 7

CRUDE DEATH RATES* FOR ALL DEATHS

CENSUS TRACTS FOR AKRON, 1980

AKRON OVERALL CRUDE DEATH RATE*: 10.8
UNITED STATES DEATH RATE, 1981: 8.8

* DEATH RATE IS PER 1,000 POPULATION



Before proceeding it must be made clear to those not familiar with the world of biostatistics and Death Rate Analysis that one cannot accurately compare the data presented in Figure 8. The main reason being that the age distribution between any two geographic areas may be different. Let me just mention that there are two other notable reasons, namely, race and sex differences. However, it has been shown that the age distribution problem by far dominates the need for adjustment and is the only one performed for this report. Thus, two areas may have same Death Rate but totally dissimilar states of health.

As an example of this phenomenon, consider three separate geographic entities A, B, and C. You can see on table 2 that all three of these areas have the same crude death rate, namely, 10.0 per 1,000 population. However, in area A all the deaths occurred to persons in their 20's, 30's, and 40's, while in area C all the deaths were to persons in their 50's or older. Obviously, area C is in better health than area A and area B. One method available to biostatisticians to "adjust" for this disparity and thus make it possible to directly compare the death rates from the different areas is called age adjusting the death rates. If age adjustment is performed on this data it can be seen that the three areas are not really equal. The death rate in area C is now much smaller than that in area A which more accurately reflects the true situation. Let me just state here that the 1980 population for the U.S. was used to age adjust the Akron, total and census tract, death data so that direct comparisons with the overall U.S. rates could be made.

TABLE 2

EXAMPLE OF AGE ADJUSTMENT OF DEATH DATA

AGE GROUP	DEATHS AREA A	DEATHS AREA B	DEATHS AREA C
0-4	40	0	0
5-14	40	0	0
15-24	20	0	0
25-34	0	40	0
35-44	0	40	0
45-54	0	20	0
55-64	0	0	20
65-74	0	0	40
75 +	0	0	40
TOTAL	100	100	100
CRUDE DEATH RATE*	10.0	10.0	10.0
AGE ADJ. DEATH RATE*	12.8	13.1	6.4

NOTE! POPULATION SIZE AND DISTRIBUTION IS IDENTICAL FOR ALL AREAS.

TOTAL POPULATION IN EACH AREA IS 100,000

* RATES ARE PER 1,000 POPULATION

Now after age adjusting the Akron data you will notice that the Akron age adjusted death rate, as shown in Figure 8, is still significantly higher than the U.S. rate. This figure, which now allows for direct areal comparisons, provides the Akron Health Director information on where the premature deaths are occurring.

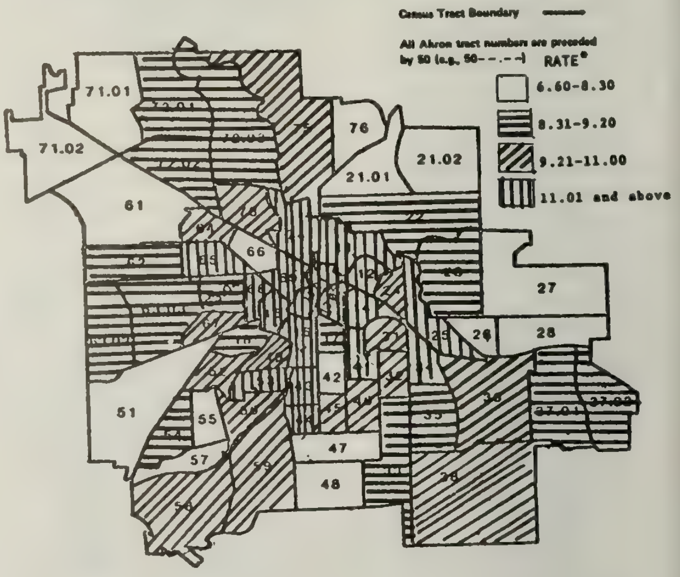
FIGURE 8

AGE ADJUSTED DEATH RATES* FOR ALL DEATHS

CENSUS TRACTS FOR AKRON, 1980

AKRON AGE ADJUSTED DEATH RATE*: 9.2
UNITED STATES DEATH RATE, 1981: 8.8

* DEATH RATE IS PER 1,000 POPULATION



Heart Disease

The leading cause of death in Akron is Heart Disease. This cause is directly amenable to Public Health intervention through hypertension screening, nutrition education, and health education programs instructing the population regarding the increased risks of heart disease related to smoking, alcohol abuse, and stress.

Figure 9 shows the crude death rates by census tracts, but as I stated before, these are not comparable across area borders. The corresponding figure where the death rates are age adjusted is Figure 10. From this figure it is clear that the Public Health focus should be directed at the City's core and from there to the North, Southeast, and Southwest.

FIGURE 9
CRUDE DEATH RATES* FOR HEART DISEASE

CENSUS TRACTS FOR AKRON, 1980

AKRON CRUDE DEATH RATE* FOR HEART DISEASE 414.0
UNITED STATES DEATH RATE FOR HEART DISEASE 345.0

* RATES ARE PER 100,000 POPULATION

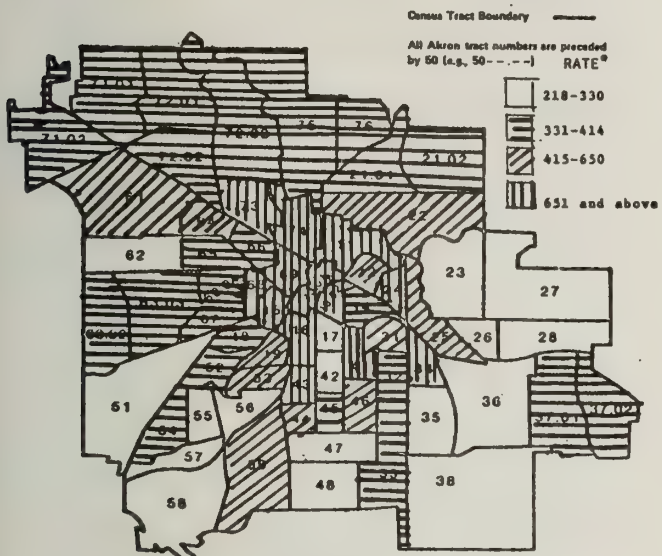
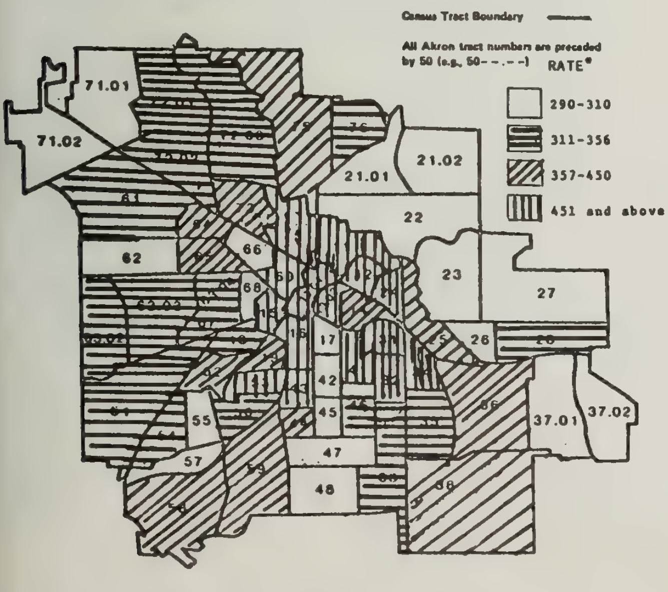


FIGURE 10

AGE ADJUSTED DEATH RATES* FOR HEART DISEASE
CENSUS TRACTS FOR AKRON, 1980

AKRON AGE ADJUSTED DEATH RATE*FOR HEART DISEASE: 356.4
UNITED STATES DEATH RATE FOR HEART DISEASE, 1981: 343.0

* RATES ARE PER 100,000 POPULATION



Malignant Neoplasms

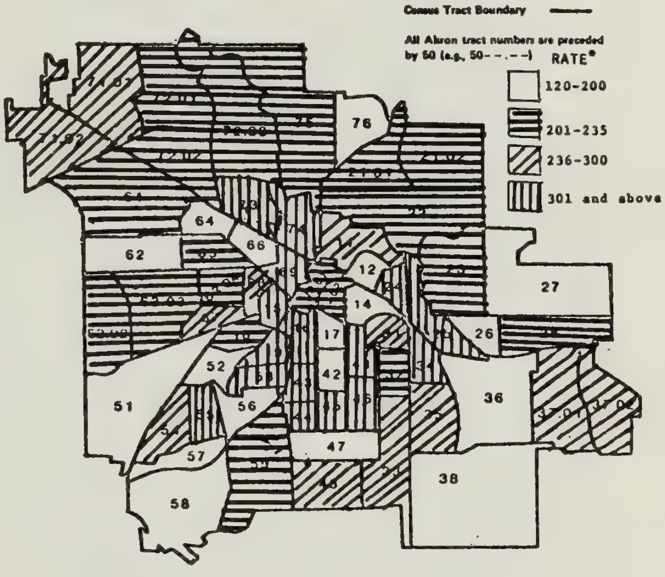
Cancer is one of the more treatable of the lethal diseases when detected early enough. Certain personal activities and environmental factors can and do affect the probability of contracting this disease. Some of these factors can be impacted by Public Health programs, such as education regarding the risks of smoking, improper nutrition, and the proper use of certain materials, such as asbestos. Figure 11 shows the crude death rates, again which is presented here only to show comparatively the changes which occur when you age-adjust this data (shown in figure 12). As it was for Heart Disease, it appears that the focus of Public Health activities should be the central core of the city and then West, Southwest, and Southeast.

FIGURE 11
CRUDE DEATH RATES* FOR MALIGNANT NEOPLASMS

CENSUS TRACTS FOR AKRON, 1980

AKRON CRUDE DEATH RATE* FOR MALIGNANT NEOPLAMS: 235.4
UNITED STATES RATE FOR MALIGNANT NEOPLASMS, 1981: 186.3

* RATES ARE PER 100,000 POPULATION



Conclusion

This paper presented arguments for a change from the traditional local Public Health methodology of looking at the City as a whole to one of small area analysis. Small area analysis of Vital Events data affords Public Health Officials with a vital tool to pinpoint areas, "hot spots" if you will. This paper did not look specifically at the aged. However, Public Health is, if one wants to look at it, in the business of helping more and more of the population reach old age. This information allows Public Health officials the opportunity to develop new programs to combat the problems found, then evaluate the outcomes, and if successful, use the programs in other less "hot" areas of the City.

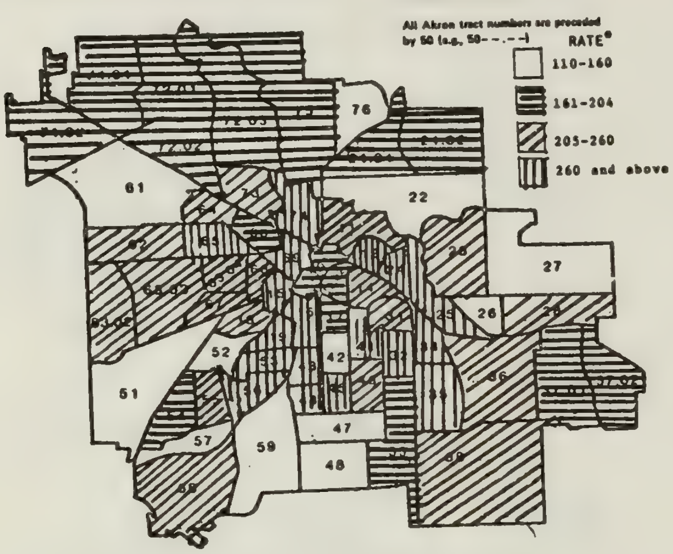
FIGURE 12

AGE ADJUSTED DEATH RATES* FOR MALIGNANT NEOPLASMS

CENSUS TRACTS FOR AKRON, 1980

AKRON AGE ADJUSTED DEATH RATE* FOR MALIGNANANT NEOPLAMS: 204.9;
UNITED STATES RATE* FOR MALIGNANT NEOPLASMS, 1981 186.3

* RATES ARE PER 100,000 POPULATION



Another important use of this type of analysis occurs when the economy of an area is declining and the need for Public Health services remains the same or even increases. This type of data when presented to the legislative bodies, the interest groups, and the public through the media can help to stem the flow of dollars out of local Public Health coffers

Just such a use of this data has been made here in Akron. The Akron Health Director has pursued a vigorous campaign to maintain the level of service in the face of a declining City population and the corresponding loss of local tax revenues. Through such a policy the Akron Health Department has maintained its level of service and is highly regarded as one of the best local Health Departments in the State of Ohio.

REFERENCES CITED

1. U.S. Department of Health and Human Services, Healthy People: The Surgeon General's Report on Health Promotion and Disease Prevention, Promoting Health/Preventing Disease Objectives for the Nation, 1982

2. Ibid.

3. Ibid.

LEADING INDICATORS: SOME PUBLIC POLICY IMPLICATIONS

Richard B. Rothenberg, Robert A. Parker, Ronald E. Aubert
Centers for Disease Control

Leading indicators may be used to convey a quantitative sense of the magnitude, intensity, and direction of health problems. Coupled with some measure of "preventability," indicators may be used to provide a basis for setting priorities. In practice, however, the perception of disease importance may be affected by the mode of presentation and the choice of statistic. The ethical framework that underlies resulting priorities may be hidden by quantification. Several examples may help to illustrate this interaction of form and content.

Consider the following series of statements about diabetes, which are based on currently available data (1):

1. In certain subgroups of the population, the prevalence of diabetes is greater than 10 percent.
2. Diabetes accounted for 8,947,000 physician office visits in 1980.
3. Diabetes played a role in almost 2 percent of deaths in 1983.
4. About one out of 4,200 Americans died with Diabetes in 1983.
5. Diabetes was the underlying cause of death in 0.02 percent of the population.
6. The rate of juvenile-onset diabetes in the United States is about one to two per 100,000, or 0.001 percent of the population.

Clearly, the importance of diabetes can rise or fall with the rhetoric. The proponent of diabetes control, or any other disease problem, may choose to focus on the ones which substantiate his concern. It would appear that the choice of indicators may be predicated on some a priori set of values.

It is of interest, then, to examine some of the leading health indices to determine what sort of perception they transmit. Using information from the National Center for Health Statistics (NCHS) data collection systems (2), we examined 10 leading indicators of mortality and illness, in (Tables 1, 2, and 3). These measures, and their potential significance for health status, are defined as follows:

1. Crude Death Rate (CDR)--The rank order of deaths in 1983 for the top 15 conditions serves as the basis for all rank order comparisons with the other nine measures.
2. Age-adjusted Death Rate (AADR)--The major effect of age adjustment is to invert the positions of stroke and accidents, possibly the result of adjustment to a standard (1940) that contains proportionally more young people.
3. First-listed Diagnosis--This estimate of the number of times that a condition appears first in the medical records sampled by the National Hospital Discharge Summary creates immediate problems with three of the 15 major causes. Since E-codes are not included, the entire N-code category (ICD9 800-994) is assigned to accidents, in brackets, to indicate an approximation. With this caveat, it shares first place with ischemic heart disease. Homicide and suicide are lost to this measure and are arbitrarily assigned a rank of 14.
4. All-listed Diagnoses--This measure, which counts all mentions of a condition, is similar to "First-listed Diagnosis," but may reflect the total impact of a disease more accurately.
5. Ratio of First-listed to All-listed Diagnoses--Since some illnesses are usually primary, while others are contributory, this measure may provide some indication the "hidden" importance of a disease.
6. Total Hospital Days--the First-listed Diagnoses only are used to tally the number of hospital days associated with each of 13 conditions. This measure is used as a surrogate for total direct costs attributable to a given condition.
7. Average Hospital Days (Length of Stay)--Similarly to "Total Hospital Days," this measure acts as an approximation of direct costs.
8. Total Years of Life Lost--This composite statistic, calculated from the death rate, the size of the

population and the expectation of life, may be viewed as an approximation of indirect cost, since it is proportional to the foregone stream of earnings.

9. Years of Productive Life Lost--This calculation is similar to "Total Years of Life Lost," but it is based on the interval between death and age 65. It may also be viewed as a measure of indirect cost.

10. Ratio of Productive Years of Total Years of Life Lost--Again, as a measure of indirect cost, this provides an estimate of the proportion of lost life that occurs during the most productive years.

If these conditions are placed in rank order for each of the measures described, several of the leading indicators differ significantly in the picture of importance they present. These differences may be quantified by calculating a rank order correlation coefficient (Spearman's r) between the CDR and each of the other nine measures (Tables 4, 5, and 6).

The CDR, the AADR, First-listed Diagnoses, and All-listed Diagnoses are highly correlated (Table 4). The CDR is not correlated, however, with the ratio of First-listed to All-listed Diagnoses. This suggests that mortality may reflect overall disease burden, but ignores illnesses that make a "hidden" contribution to morbidity.

For the measures of direct cost, CDR is correlated with Total Hospital Days, but not with Length of Stay (Table 5). Despite their imprecision these surrogates suggest that conditions have a differential impact on direct costs. For overall costs, conditions such as accidents, cancer, and heart disease predominate, but the average costs to the fewer individuals who have septicemia, perinatal conditions, or kidney disease are highest.

In assessing indirect costs, represented here by the Years of Life Lost statistics, we find the most striking results (Table 6). The CDR is significantly correlated with Total Years of Life Lost, but is uncorrelated with either Years of Productive Life Lost or with the ratio of Productive to Total. For the latter two, an entirely different set of illnesses emerges.

To summarize, the traditional measures of morbidity (hospital discharges) and mortality (death rates) emphasize the major noncommunicable conditions: heart disease, cancer, stroke, and chronic obstructive lung disease. A measure of comorbidity (ratio of First-listed to All-listed Diagnoses) highlights a different set of chronic diseases (arteriosclerosis, diabetes, and kidney disease) that contribute to increased vulnerability. Measures of indirect cost, as expected, place in prominence life-threatening conditions of the young: perinatal illness, congenital defects, and both intentional and unintentional injury. Clearly, a constellation of leading indicators can be chosen to highlight one or another set of conditions. It is an accurate representation of the fact that illnesses have a differential impact on the population.

A common solution to the problems of choice is to develop an index, or scoring system. For example, the 10 measures cited may be amalgamated into a single score (see Table 7) by summing the ranks for each indicator. The resulting list is significantly correlated with the CDR (r=0.76, z=2.83), with only minimal differences in the ranks. There are, however, several problems with amalgamation. First, the score is a weighted average of diverse measures. The assignment of weights is based on individual or institutional preferences, and the choice of weights determines the outcome. There is no "objectively true" set of weights. Second, the use of ranks ignores the distribution of values within each measure. Ranks are not evenly spaced, as shown in Table 8, which compares each value to the median value for that measure. A linear combination of ranks may distort the relationships among values.

At least four other indicators would be of importance within this context, but have been omitted for want of congruent data. Incidence measures are available only for cancer on a systematic basis. Disability days are not available, in general, in a form that permits attribution to specific ICD codes. Visits to physicians' offices are available in a number of forms, but are often reported in terms of syndromes or symptom-complexes. The same applies to the prevalence of conditions in nursing homes.

Though not presented in detail here, these four measures provide alternate views of disease importance. Influenza, neuropsychiatric conditions, and arthritis, for example, would figure prominently in this cluster of indicators (which stress occurrence and the need for nonhospital care), but do not appear on the other lists.

It may be argued that differing perceptions of disease importance arise because the indicators are static--a cross-sectional view of a process whose evolution in time is far more important. A dynamic indicator could provide a sense of the magnitude (numbers), the intensity (rates), and the direction (the temporal vector) of health status. Such indicators may illuminate our understanding of disease importance, but are likely to cause the same problems of choice.

Consider, for example, the choice between directing resources to the problems of the elderly or to the problems of infants. A calculated modification of the death rate may be used as an example of a dynamic indicator. Under a null hypothesis that each age group contributes equally to mortality, the degree of departure from the null for a given age group, measured over time, reflects its mortality experience in a manner that is directly comparable among age groups. Algebraically, this may be expressed as the ratio of the proportion of deaths in a given age group to the proportion of that age group in the population (equivalent to the age-specific rate divided by the crude rate). As shown in Figure 1, between 1900 and 1985 this ratio for infants under 1 year of age fell from 9.44 to 1.21. For those 85 years and older, it rose from 15.17 in 1900 to 21.82 in 1940, with a subsequent fall to 17.70 in 1985. Both of these trends, of course, reflect the declining mortality rates in both age groups, but the dynamic events are subject to interpretation. From 1940 to 1980, the decline is 25 percent steeper for the elderly than for infants. On the other hand, as a percentage of the starting value, the slope for the elderly has been 5 percent, compared with 17 percent for infants. Alternatively, the absolute drop has been 4.12 for the elderly versus 3.81 for infants. Clearly, dynamic indicators may be of interest, but do not free us from problems of preference in allocating resources.

In conclusion, the leading indicators of disease should be critical to policy formation, but their use must be viewed with circumspection. The mode of presentation, the choice of statistics, and the methods of combining statistics, ultimately reflect a set of human values. In many ways, this is good, for it requires us to choose priorities in an ethical, rather than in an arithmetic, framework. The real danger lies in cloaking the ethical choices in quantification, rather than making them explicit.

References

1. National Diabetes Data Group. Diabetes in America. Diabetes data compiled 1984. NIH Publication No. 85-1468, August 1985.

2. A variety of standard NCHS documents were used, including Series 13, No. 82, Series 10, No. 158, Monthly Vital Statistics Report Vol 36, No. 6, Suppl (2).

Table 1

LEADING INDICATORS OF DISEASE
MEASURES OF MORTALITY AND MORBIDITY
U.S.A., 1983

CONDITION	‹1› CRUDE DEATH RATE	‹2› AGE-ADJUSTED DEATH RATE	‹3› FIRST LISTED DIAGNOSIS (x1000)	‹4› ALL-LISTED DIAGNOSIS (x1000)	‹5› RATIO OF FIRST TO ALL
IHD	236.1	135.2	2080	5836	0.36
CANCER	189.3	132.6	2032	3235	0.63
STROKE	66.5	34.4	859	1965	0.44
ACCIDENTS	39.5	35.3	3055	5343	0.57
COPD	28.3	17.4	1099	2807	0.39
PN/INFLU	23.9	11.8	911	1436	0.63
DIABETES	15.5	9.9	675	2775	0.24
SUICIDE	12.1	11.4	---	---	---
CIRRHOSIS	11.7	10.2	95	330	0.29
ATHERO	11.3	4.6	78	963	0.08
HOMICIDE	8.6	8.6	---	---	---
PERINATAL	8.3	--	209	478	0.44
KIDNEY	8.1	4.6	128	566	23
SEPTICEMIA	5.7	3.4	92	257	0.36
CONGENITAL	5.6	--	356	854	0.42

Table 2

LEADING INDICATORS OF DISEASE
MEASURES OF DIRECT COST
U.S.A., 1983

CONDITION	‹6› TOTAL HOSPITAL DAYS (x100000)	‹7› AVERAGE LENGTH OF STAY (days)
IHD	17.7	8.5
CANCER	21.6	10.6
STROKE	10.1	11.8
ACCIDENTS	---	7.2
COPD	8.0	7.2
PN/INFLU	6.7	7.4
DIABETES	6.4	9.5
SUICIDE	---	---
CIRRHOSIS	1.0	10.1
ATHERO	0.9	11.0
HOMICIDE	---	---
PERINATAL	2.7	12.8
KIDNEY	1.5	11.8
SEPTICEMIA	1.2	13.0
CONGENITAL	2.1	5.9

Table 3

LEADING INDICATORS OF DISEASE
MEASURES OF INDIRECT COST
U.S.A., 1983

CONDITION	<8> TOTAL YEARS OF LIFE LOST (x100000)	<9> YEARS OF PRODUCTIVE LIFE LOST (x100000)	<10> RATIO OF PRODUCTIVE TO TOTAL
IHD	73.4	10.0	0.14
CANCER	77.3	18.1	0.23
STROKE	18.8	2.6	0.14
ACCIDENTS	35.4	23.1	0.65
COPD	9.5	1.2	0.13
PN/INFLU	7.1	1.7	0.23
DIABETES	5.7	1.2	0.21
SUICIDE	10.3	6.3	0.61
CIRRHOSIS	6.5	2.4	0.37
ATHEROSCLER	2.4	0.1	0.04
HOMICIDE	9.0	6.2	0.68
PERINATAL	14.4	12.4	0.86
KIDNEY	2.7	0.6	0.22
SEPTICEMIA	2.1	0.6	0.28
CONGENITAL	8.5	7.0	0.83

Table 4

RANK ORDER
MEASURES OF MORTALITY AND MORBIDITY
U.S.A., 1983

CONDITION	<2> AGE-ADJUSTED DEATH RATE	<3> FIRST LISTED DIAGNOSIS	<4> ALL-LISTED DIAGNOSIS	<5> RATIO OF FIRST TO ALL
IHD	IHD	(ACCIDENTS)	IHD	ATHERO
CANCER	CANCER	IHD	(ACCIDENTS)	KIDNEY
STROKE	ACCIDENTS	CANCER	CANCER	DIABETES
ACCIDENTS	STROKE	COPD	COPD	CIRRHOSIS
COPD	COPD	PN/INFLU	DIABETES	IHD
PN/INFLU	PN/INFLU	STROKE	STROKE	SEPTICEMIA
DIABETES	SUICIDE	DIABETES	PN/INFLU	COPD
SUICIDE	CIRRHOSIS	CONGENITAL	ATHERO	CONGENITAL
CIRRHOSIS	DIABETES	PERINATAL	CONGENITAL	PERINATAL
ATHERO	HOMICIDE	KIDNEY	KIDNEY	STROKE
HOMICIDE	ATHERO	CIRRHOSIS	PERINATAL	(ACCIDENTS)
PERINATAL	---	SEPTICEMIA	CIRRHOSIS	PN/FLU
KIDNEY	KIDNEY	ATHERO	SEPTICEMIA	CANCER
SEPTICEMIA	SEPTICEMIA	---	---	---
CONGENITAL	---	---	---	---
*Spearman's r	0.97	0.80	0.85	0.42
z-value	3.35	2.76	2.93	1.44

*based on 13 ranks

Table 5

RANK ORDER
MEASURES OF DIRECT COST
U.S.A., 1983

CONDITION	<6> TOTAL HOSPITAL DAYS	<7> AVERAGE LENGTH OF STAY
IHD	(ACCIDENTS)	SEPTICEMIA
CANCER	CANCER	PERINATAL
STROKE	IHD	KIDNEY
ACCIDENTS	STROKE	STROKE
COPD	COPD	ATHERO
PN/INFLU	PN/INFLU	CANCER
DIABETES	DIABETES	CIRRHOSIS
SUICIDE	PERINATAL	DIABETES
CIRRHOSIS	CONGENITAL	IHD
ATHERO	KIDNEY	PN/FLU
HOMICIDE	SEPTICEMIA	COPD
PERINATAL	CIRRHOSIS	(ACCIDENTS)
KIDNEY	ATHERO	CONGEN
SEPTICEMIA	---	---
CONGENITAL	---	---
*Spearman's r	0.81	0.20
z-value	2.82	0.93

*omits homicide and suicide

Table 6

RANK ORDER
MEASURES OF INDIRECT COST
U.S.A., 1983

CONDITION	<8> TOTAL YEARS OF LIFE LOST	<9> YEARS OF PRODUCTIVE LIFE LOST	<10> RATIO OF PRODUCTIVE TO TOTAL
IHD	CANCER	ACCIDENTS	PERINATAL
CANCER	IHD	CANCER	HOMICIDE
STROKE	ACCIDENTS	PERINATAL	CONGENITAL
ACCIDENTS	STROKE	IHD	ACCIDENTS
COPD	PERINATAL	HOMICIDE	SUICIDE
PN/INFLU	SUICIDE	CONGENITAL	CIRRHOSIS
DIABETES	COPD	SUICIDE	SEPTICEMIA
SUICIDE	HOMICIDE	STROKE	CANCER
CIRRHOSIS	CONGENITAL	CIRRHOSIS	PN/INFLU
ATHEROSCLE	PN/INFLU	PN/INFLU	KIDNEY
HOMICIDE	CIRRHOSIS	COPD	DIABETES
PERINATAL	DIABETES	DIABETES	STROKE
KIDNEY	KIDNEY	SEPTICEMIA	IHD
SEPTICEMIA	ATHERO	KIDNEY	COPD
CONGENITAL	SEPTICEMIA	ATHERO	ATHERO
Spearman's r	0.70	0.38	0.47
z-value	2.62	1.42	1.75

Table 7

SUMMARY SCORE USING
SUM OF THE RANKS FOR TEN
MEASURES OF DISEASE IMPORTANCE

CONDITION	SUM OF RANKS	NEW RANK	NEW ORDER
IHD	39	2	CANCER
CANCER	38	1	IHD
STROKE	58	4	ACCIDENTS
ACCIDENTS	40	3	STROKE
COPD	69	5.5	<PERINATAL>
PN/INFLU	77	8	<COPD>
DIABETES	76	7	DIABETES
SUICIDE	104	14	PN/INFLU
CIRRHOSIS	87	9	CIRRHOSIS
ATHERO	99	12	CONGENITAL
HOMICIDE	107	15	KIDNEY
PERINATAL	69	5.5	ATHERO
KIDNEY	95	11	SEPTICEMIA
SEPTICEMIA	103	13	SUICIDE
CONGENITAL	91	10	HOMICIDE

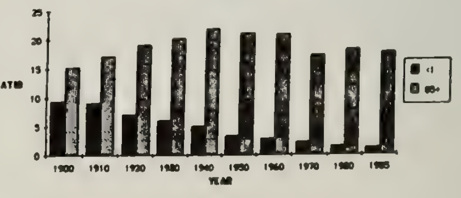
Table 8

LEADING INDICATORS OF DISEASE
RATIO RELATIVE TO MEDIAN VALUE
U.S.A., 1983

	<1> CRUDE DEATH RATE		<2> AGE-ADJUSTED DEATH RATE		<3> FIRST LISTED DIAGNOSIS
IHD	19.5				
CANCER	15.6	IHD	11.9	ACCIDENTS	4.5
STROKE	5.5	CANCER	11.6	IHD	3.1
ACCIDENTS	3.3	ACCIDENTS	3.1	CANCER	3
COPD	2.3	STROKE	3	COPD	1.6
PN/INFLU	2	COPD	1.5	PN/INFLU	1.4
DIABETES	1.2	PN/INFLU	1.1	STROKE	1.3
SUICIDE	1	SUICIDE	1	DIABETES	1
CIRRHOSIS	0.97	CIRRHOSIS	0.89	CONGENITAL	0.53
ATHERO	0.93	DIABETES	0.87	PERINATAL	0.31
HOMICIDE	0.71	HOMICIDE	0.75	KIDNEY	0.19
PERINATAL	0.69	ATHERO	0.4	CIRRHOSIS	0.14
KIDNEY	0.67	KIDNEY	0.4	SEPTICEMIA	0.14
SEPTICEMIA	0.47	SEPTICEMIA	0.3	ATHERO	0.12
CONGENITAL	0.46				

Figure 1

RATIO OF PROPORTION OF DEATHS IN AN AGE GROUP
TO PROPORTION OF THE POPULATION IN THE AGE GROUP
1900-1985



PLACE OF DEATH DATA IN HEALTH POLICY

R. D. Nashold, Wisconsin Center for Health Statistics

Historically, public health has focused on community based efforts and this has provided incentive to develop measures of community health. Age, sex, and cause-specific mortality rates have been widely used as indicators of community health status or as components of more complex index development efforts. Therefore, it is no surprise that place of death has always been a recommended data item on the United States Standard Death Certificate.

Place of death has additional significance when considering violent death because place and cause may be linked. Analyses of violent deaths have their origins in the early history of public health and the recording of death. Violent death studies are receiving more attention because of growing concern about the epidemiology of violence. A good recent example is a study of geographic variations in motor vehicle fatalities.[1] Interest is clearly demonstrated by the establishment of the Division of Injury Epidemiology and Control in the Centers for Disease Control.

Environmental health studies that focus on place of death also go back in time, e.g., John Snow's classic epidemiologic study of cholera deaths that occurred around the Broad Street pump[2] in London in 1884. Again, with increasing interest in environmental research, place of death has added importance. However, many environmental health studies face a well known data dilemma. Rates are usually necessary to make useful comparisons and these rates should preferably be standardized by age, sex and race. To do this accurately requires a relatively large number of cases or deaths. A frequency of sufficient magnitude may only be yielded by a metropolitan area, region or state.

A recent example of this data problem in Wisconsin involved amyotrophic lateral sclerosis (Lou Gehrig's Disease) and the use of a lawn fertilizer that contains heavy metals. The fertilizer is produced and widely used in Milwaukee County, so comparisons of mortality from the cause group were made between this and other geographic areas (Table 1, Figure 1). The number of ALS deaths were too few to allow for standardization of death rates at the county or city level and low frequencies would even result in questionable standardization for some states. Therefore, five-year annual average crude rates were computed as an alternative.

Table 1. Amyotrohic Lateral Sclerosis (ALS)* Mortality by Place of Death, Five-Year Annual Average, 1980-1984 (Resident Data)

Place of Death	Average Frequency	Crude Rate** Per 100,000 Pop.
United States	2,911	1.25
Wisconsin	72	1.51
Milwaukee County	14	1.49
Minnesota	59	1.41

*ICD 335.2 includes a few motor neurone disease deaths that are not ALS.

**No statistically significant differences beween rates at the .05 level of probability.

There are other common data problems in such studies involving both numerators and denominators. For example, place of death may be a poor indicator of exposure to a hazard, since it often does not correspond with place of usual work or residence. Base population data are frequently not available and must be estimated. The problems encountered in using place of death data in environmental health studies may be illustrative of the problems to be faced when using it in other areas of health policy determination.

Recently, there has been more interest in place of death as a reflection of characteristics or quality of care in a given setting or facility.[3,4] In many states such data have been available from vital records systems and from annual health facility surveys for periods ranging from a few years to a quarter century. Wisconsin examples appear in Tables 2 and 3 and Figures 1 and 2.

The number of deaths in Wisconsin hospitals decreased from 1965 to 1985 by 15 percent, whereas the number of hospital discharges from 1970 to 1985 (1965 data not available) decreased by 11 percent. When death rates are calculated per 1,000 discharges between 1970 and 1980, the rate declined from 38.6 to 33.5 or by 13 percent. It then remained essentially stable until 1984. However, during a single year, from 1984 to 1985, the rate rose nearly seven percent (Table 2, Figure 2).

Table 2. Hospital Deaths in Wisconsin, 1965-1985 (Occurrence Data)

Year	Total Deaths	Hospital Deaths Number	Hospital Deaths Percent	Hospital Discharges	Hosp.Death Rate*	Percent Change In Rate
1965	40,024	26,996	67.5	NA	NA	
1970	40,829	27,944	68.4	725,441	38.6	-10.4 (70-75)
1975	39,939	25,946	65.0	752,037	34.6	-3.2 (75-80)
1980	40,839	25,700	62.9	766,924	33.5	
1981	40,414	25,313	62.6	756,182	33.5	
1982	40,153	24,669	61.4	751,721	32.8	-0.6 (80-84)
1983	40,968	24,621	60.1	739,616	33.3	
1984	40,954	23,302	56.9	700,729	33.3	+6.6 (84-85)
1985	41,450	22,955	55.4	646,349	35.5	

*Rate per 1,000 discharges.

Table 3. Nursing Home Deaths in Wisconsin, 1965-1985 (Occurrence Data)

Year	Total Deaths	Nursing Home Deaths Number	Nursing Home Deaths Percent	Average Daily Census	Death Rate	% Change in Death Rates
1965	40,024	4,159	10.4	17,645	23.6	+4.7 (1965-70)
1970	40,829	6,231	15.3	25,176	24.7	
1975	39,939	8,231	20.6	45,342	18.2	-26.3 (1970-75)
1980	40,839	8,679	21.3	48,008	18.1	-0.5 (1975-80)
1981	40,414	8,744	21.6	47,978	18.2	
1982	40,153	8,841	22.0	48,465	18.2	+16.6 (1980-84)
1983	40,968	9,521	23.2	49,068	19.4	
1984	40,954	10,373	25.3	49,270	21.1	+10.0 (1984-85)
1985	41,450	11,312	27.3	48,834	23.2	

*Per 100 average daily census.

When looking at the number of Wisconsin nursing home deaths, it appears there has been almost a steady increase from 1965 to 1985. Over the two decades, nursing home deaths increased 172 percent; however, the average daily census of nursing home patients increased even more rapidly, 177 percent over the same time period. Death rates based on the average daily census decreased from 1970 to 1975, remained stable from 1975 to 1982, then increased 27 percent from 1982 to 1985. Ten percent of this increase occurred in the single year between 1984 and 1985 (Table 3, Figure 3).

There has been speculation that this change may be due in part to changes in the prospective payment system.[5,6] It should also be noted that the increase in death rates might in part be explained by the fact that the residents are older and sicker. Those aged 85+ increased by 14 percent from 1980 to 1985; those requiring skilled care increased almost 17 percent; and those who were non-ambulatory increased nearly 26 percent (Table 4, Figure 4).

During 1986, the Joint Commission on Accreditation of Hospitals (JCAH) announced its intent to include outcome criteria as part of its accreditation procedure. This is likely to include data on deaths, infections and disabilities. Previously JCAH focused its surveys on structure and process such as equipment, staffing patterns and record keeping. Studies have shown that process and outcome are poorly correlated[7,8] so this decision may seem overdue. On the other hand, it has been shown that crude outcomes, such as death rates for specific conditions, may be meaningless, unless adjustments are made for severity of disease. Severity of disease is the most important predictor of death.[9] Mortality rates for hospitals in the United States were released by the Health Care Financing Administration in 1986.[10] These data became highly controversial and stimulated discussion on the use of such data. On April 21-22, 1987 an "Executive training program on peer review outcome data" took place in Washington, D.C. In preparation for this meeting, the American Medical Review Research Center produced a Draft Statement on Public Release of Mortality Data. In relation to the use of hospital mortality data as an indicator of quality of care, this document discusses the likelihood of both "false negatives" (failure to detect poor quality when it exists) and "false positives" (hospitals labeled erroneously as providing poor quality care when higher mortality rates are actually due to the severe mix of patients treated). This paper also discusses the problem of randomness, or chance variation in hospital mortality data, the quality of mortality data and appropriate adjustment factors such as: age, sex, race, average length of stay and case mix. In addition, this paper provides useful references, i.e., Donabedian[11] and examples of computer programs that are available for analyzing hospital mortality, disease staging and DRG assignment.

Table 4. Changing Characteristics of Nursing Home Residents in Wisconsin, 1980-1985 (Occurrence Data)

Year	Total Residents	Residents Aged 85+	Percent Aged 85+	Percent Skilled Care	Percent Non-Ambulatory
1980	48,488	17,331	35.7	51.8	31.9
1981	48,670	18,214	37.4	53.2	35.6
1982	48,651	18,354	37.7	54.6	37.1
1983	49,227	19,319	39.2	57.0	37.6
1984	49,690	19,447	39.1	58.6	38.5
1985	48,728	19,784	40.6	60.5	40.1
Percent Increase	0.5	14.2	13.7	16.8	25.7

Some recommended adjustment data are available at the state level, i.e., hospitals with specialized services. Such hospitals are likely to attract the most critically ill patients and as a result, although they might provide the best patient care they may also have the highest mortality rates. Regarding infant mortality in Wisconsin hospitals from 1980 to 1985, the proportion of such deaths that occurred in 12 perinatal center hospitals ranged from about 61 percent to 63 percent (Table 5, Figure 5). These statistics are cited as an indication of the success of regionalization of perinatal services within the state. A larger proportion of high risk infants are being treated in perinatal centers. The infant mortality rate in the state declined from 10.3 to 9.1 per 1,000 live births over this same period.

In contrast, only about 13 to 15 percent of acute myocardial infarction deaths occurred in Wisconsin hospitals that have cardiac intensive care units (CICU). The proportion of deaths that occurred in these hospitals has remained essentially constant from 1980 to 1985. Clearly, additional variables, such as severity of disease, must be explored in conjunction with the mortality rates if they are to have significance in answering quality of care questions (Table 6, Figure 6).

Location of death within hospitals (Table 7) may also be of policy/program interest, particularly when cross-tabulated by age (Table 8). Over the period 1980 to 1985, there has been a decrease in Wisconsin inpatient hospital deaths and in those patients who are pronounced dead on arrival at the hospital. In the same period, deaths in emergency departments (E.D.s) increased. The decrease in the number of inpatient deaths is not surprising because the number of inpatients has decreased. The increase in E.D. deaths cannot be explained by an increase in E.D. visits. Over the past five years, E.D. visits have actually decreased slightly.

Table 9 shows how deaths within hospitals vary by major diagnoses and age-groups (<65 and 65+). The relationships between these frequencies are largely what is expected. For example, the highest proportion of deaths anywhere in the hospital is for those age 65+. As also expected, fatal injuries are the exception with more deaths for those below age 65. It can also be seen that a high proportion of emergency department deaths are due to heart disease. Obviously, deaths vary considerably by age and diagnosis.

Table 5. Infant Mortality* in Hospitals With and Without Neonatal Intensive Care Units (NICU)** in Wisconsin, 1980-1985 (Resident Data)

	Total		Hosp. with NICU		Hosp. W/O NICU		Other	
Year	Number	Rate***	Number	Percent	Number	Percent	Number	Percent
1980	772	10.3	471	61.0	229	29.7	72	9.3
1981	766	10.3	480	62.7	232	30.3	54	7.0
1982	687	9.4	412	60.0	220	32.0	54	7.9
1983	686	9.6	424	62.0	204	29.7	58	8.5
1984	697	9.9	429	61.5	203	29.1	65	9.3
1985	653	9.2	412	63.1	185	28.3	56	8.7
Percent Change 1980-85		-10.7		+3.4		-4.7		-6.5

*Based on infant deaths occurring in Wisconsin in each calendar year.
**Neonatal Intensive Care Unit hospitals consist of eleven hospitals with perinatal centers and the University of Wisconsin Hospitals and Clinics, Madison.
***Rate per 1,000 live births.

Table 6. Acute Myocardial Infarction Mortality (ICD 410) in Hospitals With and Without Coronary Intensive Care Units (CICU) Wisconsin, 1980-1985 (Resident Data)

	Acute Myocard.	Hosp. with CICU*		Hosp. w/o CICU		Non-Hospital	
Year	Deaths	Number	Percent	Number	Percent	Number	Percent
1980	6,684	867	13.0	3,361	50.3	2,456	36.7
1981	6,482	823	12.7	3,282	50.6	2,377	36.7
1982	6,365	827	13.0	3,273	51.4	2,265	35.6
1983	6,094	903	14.8	3,095	50.8	2,096	34.4
1984	6,090	861	14.1	3,072	50.4	2,157	35.4
1985	6,060	816	13.5	3,040	50.2	2,204	36.4

*Fourteen hospitals with a CICU consisting of five or more staffed beds.

Table 7. Hospital Deaths by Patient Location in Wisconsin, 1980-1985 (Resident Data)

Year	Hospital Deaths	Inpatient Deaths		Emerg. Dept. Deaths		Dead on Arrival	
		Number	Rate[1]	Number[2]	Rate[3]	Number	Rate[4]
1980	24,711	20,102	25.0	1,329	90.1	3,280	69.6
1981	24,355	19,806	24.7	1,594	114.1	2,953	62.4
1982	23,744	19,194	23.8	1,767	131.2	2,783	58.7
1983	23,609	18,926	24.0	2,031	152.2	2,652	55.9
1984	22,383	17,819	23.0	2,164	153.3	2,400	50.4
1985	22,023	17,237	24.8	2,431	191.1	2,355	49.3
Percent Change			-0.8		+112.1		-29.2

[1] Rate per 1,000 discharges.
[2] Includes a small but unknown number of other outpatient deaths.
[3] Rate per 1,000 ED visits.
[4] Rate per 100,000 population.

Table 8. Hospital Deaths by Patient Location and Age in Wisconsin, 1980-1985 (Resident Data)

Year	Hospital Deaths	Inpatient Deaths	Emerg. Dept. Deaths*	Dead on Arrival
		Below Age 65		
1980	7,662	5,555	620	1,487
1981	7,466	5,355	748	1,362
1982	7,043	5,002	813	1,228
1983	6,885	4,858	873	1,145
1984	6,686	4,695	948	1,045
1985	6,471	4,512	997	962
Percent Change	-15.5	-18.8	+38.6	-35.3
		Age 65+		
1980	17,049	14,547	709	1,793
1981	16,888	14,451	846	1,590
1982	16,701	14,192	954	1,555
1983	16,724	14,068	1,158	1,498
1984	15,697	13,126	1,126	1,355
1985	15,552	12,725	1,434	1,393
Percent Change	-8.8	-12.5	+102.3	-22.3
		Age 85+		
1980	3,689	3,353	82	251
1981	3,783	3,432	92	259
1982	3,749	3,388	125	236
1983	3,709	3,338	145	226
1984	3,456	3,079	179	198
1985	3,404	3,004	189	211
Percent Change	-7.7	-10.4	+130.5	-15.9

*Includes a small but unknown number of other outpatient deaths.

Table 9. Hospital Deaths by Major Cause Groups Less Than Age 65 and 65+ by Patient Status in Wisconsin, 1985 (Resident Data)

Diagnosis	Total		Inpatient		Emerg. Dept.		Dead on Arr.	
	<65	65+	<65	65+	<65	65+	<65	65+
Total	6,471	15,552	4,512	12,125	997	1,434	962	1,393
Cancer	1,877	3,132	1,783	2,993	33	53	61	86
Heart	2,134	8,612	1,097	6,289	563	1,198	474	1,125
Stroke	250	1,348	231	1,279	15	47	4	22
Chr.Obst.Pul.	122	633	98	546	6	35	18	52
Pneumonia	101	581	91	570	8	7	2	4
Injuries	523	281	172	201	187	39	164	41
All Other	1,464	965	1,040	247	185	55	239	63

Table 8 shows a dramatic increase in the number of deaths in emergency departments particularly for the old (age 65+) and the very old (age 85+). If it could also be shown that the proportion of old and very old being treated in E.D.s has increased rapidly, this could explain the increasing number of deaths. Unfortunately, such data are not readily available in Wisconsin. Nevertheless, other questions are raised. Has there been an improvement in medical transport so that more critically ill patients arrive alive but do not remain so for long? The aged are far more likely to be among the most acutely ill. Has there been closer adherence to the definition of an ambulance as conveyance for the sick and injured rather than a vehicle for transporting the known dead?

The death certificate does not contain information on source of payment; however, those age 65+ are covered by Medicare and almost one-fourth of those age 85+ are also on Medicaid. Therefore, despite the other known facts, some additional rather harsh questions are raised about E.D. deaths among the elderly. For example, are elderly patients discharged too soon as inpatients and brought back later in such extreme condition that they die in the emergency department? Even more disquieting questions are raised about resuscitation. It is sometimes suggested or implied that such techniques might be performed more aggressively on moribund elderly because Medicare and Medicaid can be charged for the procedures. To answer such questions, it would be necessary to carry out carefully designed studies involving peer review.

Since the implementation of diagnosis related group (DRG) prospective payment, hospitals have been accused of discharging persons "quicker and sicker."[12] Statistics bear out the fact that people are being discharged faster, but the key question is, "Are they being harmed by it?" An indicator of this might be an increase in death rates for those age 65 and over. If this were to occur, it would most likely appear for the most vulnerable, namely, those age 85+ and a higher proportion of these deaths might occur outside of hospitals. From 1980 through 1985, the mortality rate for those age 65+ in Wisconsin remained essentially stable, ranging only from 51.2 to 53.1 per 1,000 population. For the population 85 and over, the mortality rates decreased from 1980 to 1982, then remained essentially constant from 1982 through 1985

From 1980 to 1985 in Wisconsin there was a decline of nearly 20 percent for inpatient hospital death rates for those age 85+. Over this same period, Wisconsin nursing home mortality rates increased more than 28 percent with nearly 20 percent of the increase occurring between 1983 and 1985 (Table 3). As previously noted in Table 4, from 1980 to 1985 the age 85+ residents of nursing homes increased over 14 percent. The proportion requiring skilled care increased almost 17 percent and the proportion of non-ambulatory increased nearly 26 percent. Clearly, this represents a rather dramatic increase in the most frail and vulnerable residents of nursing homes and accounts for an unknown proportion of the increased mortality.

Table 10. Population & Decedents Aged 65+ and 85+ in Wisconsin, 1980-1985 (Resident Data)

		Decedents	
Year	Population	Number	Rate/1000
	Age 65+		
1980	564,200	29,966	53.1
1981	575,750	29,733	51.6
1982	585,250	29,948	51.2
1983	595,000	30,941	52.0
1984	604,000	30,918	51.2
1985	617,000	31,674	51.3
Percent Increase	9.4	5.7	-3.4
	Age 85+		
1980	55,637	8,882	159.6
1981	58,100	9,019	155.2
1982	60,600	9,207	151.9
1983	63,100	9,647	152.9
1984	65,500	9,875	150.8
1985	68,000	10,370	152.5
Percent Increase	22.2	16.8	-4.5

*Estimates prepared by the Center for Health Statistics, Wisconsin Department of Health and Social Services (DHSS).

Another health policy area for which it is appropriate to review place of death is in assessing the use of home health services and hospice services. These services are expanding and, as would be expected, the proportion of home deaths is also increasing. The typical daily caseload for home health agencies rose from about 12,000 patients to about 20,000 or 67 percent during the four years for which data are available (Table 11). An unduplicated count of patients receiving home health care during the calendar year 1985 was approximately 60,000. During this period there are approximately 4,200 deaths among these patients for an annual death rate of seven percent. Hospice services are not licensed by the State of Wisconsin so little data exists. There are 10 hospices certified for Medicare and probably about five times that number in existence and the numbers are increasing.

Table 11. Home Health Agency Patients in Wisconsin, 1982-1986 (Occurrence Data)

Year	Number of Patients Daily Caseload*
1982	12,176
1983	16,040
1984	15,966
1985	18,060
1986	20,273
Percent Change	66.5

*Caseload for typical day--Dec. 30,1982-1983, May 1, 1984-86. Patient numbers may reflect seasonality.

Deaths at home decreased during the sixties, remained rather stable during the seventies and have been increasing during the eighties (Table 12, Figure 8). From 1980 to 1985, home deaths rose nearly 20 percent. Of course, it is pointed out that the health care system is responding to patient preference with growing interest in living wills, a home setting for the terminally ill, and in cost containment for the terminally ill and others. Comparative costs by where treatment or care is provided is an obvious area for further research.

Table 12. Deaths at Home in Wisconsin, 1961-1985 (Occurrence Data)

Year	Home Deaths	Percent of All Deaths
1961	9,213	27.7
1962	9,209	24.1
1963	8,875	22.4
1964	8,288	21.3
1965	7,943	19.8
1966	6,864	17.0
1967	6,172	15.6
1968	5,928	14.3
1969	5,611	13.7
1970	5,537	13.6
1971	5,164	12.7
1972	5,395	12.8
1973	5,137	12.4
1974	5,019	12.2
1975	4,886	12.2
1976	5,127	12.8
1977	4,955	12.6
1978	5,039	12.5
1979	4,840	12.4
1980	4,854	11.9
1981	4,971	12.3
1982	5,102	12.7
1983	5,413	13.2
1984	5,711	13.9
1985	5,803	14.0

In 1989, a new standard death certificate will be implemented in most states. Extensive review of data items has taken place and according to recommendations, items 9a through 9d will involve place of death. In view of growing interest, states may wish to include greater specificity in place of death categories. For example, a separate category for emergency department deaths is needed rather than including it with other hospital outpatient deaths. Nearly all of the deaths coded in the combined category are emergency department deaths so a more specific title is appropriate. As more former inpatient procedures become outpatient procedures, it might also be useful to identify changes in out patient mortality as a separate category.

In summary, trends in place of death data show shifting patterns (Figure 9) that have relevance for health policy. Researchers should focus on obtaining more specific categories for place of death and on obtaining data from multiple sources for health policy research.

Figures 1 through 9 are available upon request from the Center for Health Statistics, P. O. Box 309, Madison, Wisconsin 53701-0309.

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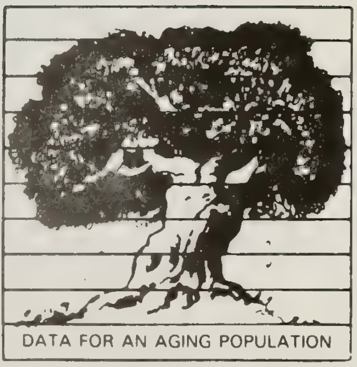
Session O

Issues and Innovations in Epidemiologic Measures for Older Populations



DATA FOR AN AGING POPULATION

IMPROVEMENTS IN THE QUALITY OF CENSUS AGE STATISTICS FOR THE ELDERLY

Gregory Spencer, Bureau of the Census

This paper details the results of some recent research at the Census Bureau into the possibility of improving the quality of census age statistics. Several detailed procedures are described which may serve to particularly improve the accuracy of age data for the elderly. Though the emphasis here is on various shortcomings of the data, it is important to understand that the decennial age statistics are for the most part of very high quality.[1] Even so, problems of some consequence or severity have probably always existed in decennial census age data for the old. For example, the National Center for Health Statistics does not use the 1980 Census data for those aged 95 years and older because "...the data from the census...are scanty and unreliable...."[2] The Census Bureau itself, for its population estimates, redistributed the reported 1980 data for those aged 75 and older as the statistics "...showed significant misreporting of age at certain ages."[3] A knowledgeable summary of the sorts of problems which exist, with particular emphasis on the problems in the 1980 Census data for the 85 years and older population, are included in a recent book by Rosenwaike.[4]

One ramification of deficient age data is that, if enough people of some reported age are truly a different age, then this admixture of people at different stages of the life cycle can result in aberrant socio-economic characteristics being attributed to both age groups. Such a possibility has been demonstrated for the centenarian population by research which illustrated the great differences in marital status, household relationship, and living arrangements of actual centenarians when compared with those of the centenarian populatin as enumerated by the 1980 Census.[5] This is an extreme example since half the census centenarians apparently were actually younger.

Two particular sources of error in the 1980 Census age statistics will be examined. These are: 1) those who mistakenly reported an inappropriate age; 2) those without an age whom the Bureau's edit procedures assigned or "allocated" an unreasonable age.

Why Are There Any Problems With The Age Data?

Naturally, very little can be done to correct for deliberate misstatement of age. Fortunately, the examination of thousands of original forms indicated that scarcely anyone seemed to purposefully misstate their age. Further, everyone seemed able to provide an age. No person on any of these forms ever reported that their age was unknown. The difficulty is with that small fraction of the population which make errors in the process of coding their age or year of birth on the census form. There will probably always be such people. However, these difficulties may well have become more serious since the 1960 Census. The reason is that census data collection procedures have changed from the information primarily being collected by personal interview in 1960 to now being obtained by a relatively impersonal mail-out and mail-back procedure. A personal visit by an enumerator should increase the probability that unreasonable age responses could be ascertained. It is much more difficult to correct mistakes on mailed-back forms because of the wide range of possible real circumstances found in the population. It would not be appropriate to simply asume that unusual cases were errors.

The centenarian data are a good example of the impact of this change in census procedures. In 1960, the last predominately enumerator conducted census, the count of centenarians was 10,369. That was probably too high as research suggested that the actual number was less than 5,000.[6] But that sort of error pales by comparison with the centenarian problem in 1970, the first primarily self-enumeration census. That census, where most of the data were collected from forms returned by households, found 106,441 centenarians while the correct number was probably less than 8,000. As Siegel and Passel noted, "...the overstatement of the number of centenarians in that census appears to have resulted principally from a misunderstanding on the part of certain respondents as to the proper manner of filling out the census forms..." In other words, some respondents mailed back incorrect age information and it was very difficult for the Census processing staff to determine which responses were errors. Both the age question and the procedures used to edit those responses were redesigned before the 1980 census. These changes resulted in a considerable improvement as the 1980 census count of centenarians was reduced to 32,123. Recent studies indicate that the correct number was nearer 15,000. [7]

It is interesting to note that the proportionate error in the centenarian count in 1980 was not much different from that in 1960. In each instance, the census count of centenarians was about twice the true centenarian population. This could be taken to suggest that all the improvements in Census techniques since 1960, plus the enhanced abilities of the general population to fill out forms, have just managed to return the accuracy of the age data to its levels in the last enumerator-conducted census.

Edit And Allocation Procedures

All users of census data know that there is no longer any such category of data as "unknown". Most also realize that, in fact, some share of the data for any particular census item were originally unknown. Subject-matter experts at the Census Bureau have developed edit and allocation procedures to assign a reasonable value to each non-response or inconsistent response (i.e. children older than their parents). The specific nature of these procedures are essentially unknown outside the Census Bureau, yet their impact can be considerable. It is well-known, for instance, that 2.9 percent of the U.S. population in 1980 had an age assigned them by these allocation procedures. That may seem inconsequential, but it translates to nearly 7 million people for whom these procedures had to create a reasonable age. Any shortcomings in the application of the edit procedures could clearly affect the quality of the age data. That is especially true for the elderly where the edited cases are more prevalent. An age was created for 4.0 percent of the 65 and over population in 1980. The equivalent figure for the 85 and over was 5.4 percent. It was 26.6 percent for the centenarian population.

One possible explanation of this rise in allocation rates with increased age is that allocation rates truly do rise with increases in age because the elderly are more likely to make coding errors or fail to attempt to answer the question. If so, one way to improve the quality of the data for the elderly would be to reduce the non-response rate. That is so because it is well-known that nearly everyone of any age can write their age correctly on the form. The problem is finding a way to enable more respondents to accurately code their age by darkening the correct circles on the questionnaire.

It should be realized that reduced non-response rates, in and of themselves, do nothing to fix those mistaken responses which produce an acceptable age. For example, 24,000 people actually reported themselves as centenarians in the 1980 Census, although we now believe no more than 15,000 were truly so old. It appears that some of the erroneous but acceptable ages can be corrected through the use of special consistency edits. These are used to make sure that children are younger than their parents, and the like. Therefore, two different research tasks needed to be undertaken. The first was to attempt to reduce the non-response rates to the age question as it is likely that people report a more correct age for themselves than we can create for them. The second was to utilize the best possible allocation procedures to most accurately assign values for those missing or inconsistent ages.

Can the Non-response Rate to the Age Question Be Reduced?

Each respondent's age could be ascertained in 3 different ways from the 1980 census questionnaire: written age, written year of birth, and coded year of birth. Each person's coded quarter of birth was also collected. The final product of all these questions was of course a respondent's age. Notice that a respondent's age was typically derived indirectly from the person's coded year and quarter of birth. This rather complicated procedure has been used in the last several censuses because Census Bureau research prior to 1960 suggested that age derived from the year of birth data displayed less heaping at ages ending in 0 or 5 than did the directly reported age data.

One theoretical advantage of this design was that the availability of both year of birth and month of birth data permitted the calculation of the person's exact age to within 3 months. The use of that particular degree of age exactitude has never been widespread. At the Census Bureau it was primarily used to analyze data on marital history or on the age of mothers at the birth of their children. Both those questions have been deleted from the 1990 census, and the Bureau no longer has any subject-matter use for such precise age statistics.

In view of this, it seemed appropriate to reassess the justification for constructing the age question in such a circuitous fashion. If age heaping has become sufficiently low, then it would be possible to once again obtain the age of respondents directly rather than estimate it from the year of birth data. The evidence is quite strong that age heaping is a minor problem these days. [8] Additionally, because of the dearth of uses for the coded quarter of birth item; it seemed reasonable to reconstruct the question so as to obtain coded responses to both age and year of birth. The presence of both responses would greatly enhance our ability to check them for internal consistency. Also, the non-response rate to the question might be reduced if people were provided an extra opportunity to correctly code their age response.

For these reasons, we have been testing a redesigned age question. It asks people to first print and then code both ag e and year of birth. Our first concern in the evaluation of this question was to determine if the non-response rates were reduced. There was no proof that a respondent who could not code their year of birth correctly would be able to turn right around and be able to code their age. If this did not occur, there would be less justification to ask people to essentially give us the same answer twice. However, if carelessness was the cause of some of the non-response, then there could be hope of data improvement. The results of the 1986 Test Census have been very positive. Age and year of birth, when considered as separate items, each had a non-response rate of about 3.2 percent. This was not much different from the 2.9 percent non-response to the 1980 census question. But, when the items were uses in conjunction, the non-response rate dropped to only 1.8 percent. This 40 percent improvement was very encouraging.

Our second concern was to determine if the coded age and coded year of birth for individuals were consistent. If they were not, then we would have to choose which of the two acceptable responses was "correct". Again, the results of the test censuses were positive. The age statistics were almost always perfectly consistent with the year of birth data in the 1986 test censuses. As an example, only 0.9 percent of respondents over age 70 reported data which were inconsistent by more than one year. In keeping with the procedures of the last several censuses, when both responses are acceptable but inconsistent, we decided to derive the persons's age from their year of birth.

In summary, the redesigned question we are currently testing significantly reduced the non-response rates for age and simultaneously provided internally consistent data.

Can We Make Any Improvements In The Edit And Allocation Procedures?

Another possible mechanism by which the data quality might be enhanced would be to improve the accuracy of the procedures used to allocate values for missing data. The edits used in 1980 were subjected to an extensive review. In general, they did a very good job of assigning reasonable values. Several problems were found which reduced the quality of the age data.

The first might be described as the problem of the elderly children. To comprehend this problem one must understand that each respondent had to code whether they were born in the nineteenth or twentieth century. On some occasions, the entire household would mistakenly code themselves as having been born in the nineteenth century and not the twentieth. The result was that everyone in the household had reported themselves as being over age 100. The edit rules then blanked the age of anyone reported to be over age 112. What happened, in households with young children present, was that the adults would have their age blanked, but children who were really under age 13 were permitted to remain at ages 100 to 112. Later in the edit procedures an age had to be allocated to all adults without one. Logically enough, the age of adults was usually estimated from the age of the oldest child in the household. Since, in these few cases, this oldest child was already at least age 100, their parents would again become older than age 112. When this happened, the adult would have been assigned the age of 112. The result was that the centenarian population in the 1980 Census contained a number of families where the parents were both 112 while their children were 100 to 112. In fact, almost 5 percent of the 1980 census centenarians were such elderly 'children'. That means, at a minimum, that another 8 to 9 percent of the centenarians were the parents of these children. In other words, nearly 15 percent of the centenarians in 1980 were created through this one process. Since families with young children are clearly at a different stage of the life cycle than are true centenarians, the centenarian data must be seriously flawed. Another important point is that those children, 5 percent of centenarians, were not allocated to those old ages because the age they provided was deemed acceptable. This is an example of why it would be incorrect to assume that the unallocated age data were much more accurate than the total data set.

The solution to this difficulty was simply to restrict the acceptable age range for children. During the processing of the 1990 census no child, stepchild, or grand-child will be permitted to be over age 90. That restraint is unlikely to eliminate any true cases. Only 0.1 percent of all children were over age 70 in the 1986 test censuses.

Another difficult editing situation in 1980 was the result of erroneous responses of "father/mother" to the census question on relationship. This response was supposed to refer only to the householder's parents who reside with him/her. If the spouse's parent's reside in the household, they are supposed to be coded as an "other relative" of the householder. In theory, then, the "father/mother" category should only encompass about half those parents who live with their adult children. Many users of this information are unaware of this distinction. This particular problem really has no effect on the quality of the age statistics.

That we do have an age problem with this relationship category, however, is evinced by the fact that, in the 1986 National Content Test, about 13 percent of the "father/mother of householder" respondents were under age 30. This is impossible since the Census requires the householder to be at least age 15. Therefore their parent should be at least 15 years older than them, or over age 30. It turns out that many of these impossibly youthful father/mothers were really children of the householder. They were reported as father/mother because the householder was reporting that he/she was the father/mother of these children. Another significant group of these youthful father/mothers were wives who reported themselves as 'mothers' since they were also mothers. In the 1980 census the deleterious impact of these cases was minimized as long as the mistaken father/mother reported an age under 30. All such cases resulted in the relationship response being blanked. There was then at least some chance that our edit procedures could assign these people their original relationship. For the next census, revised edit specifications have been introduced which are intended to return more of these mistaken father/mothers to their original status as children or spouse of the householder.

The most difficult cases are those where such erroneous father/mothers did not report acceptable ages. Such cases were accepted as legitimate fathers or mothers in 1980. They were eventually assigned an appropriate age based on the age of the householder. At a minimum this age would usually have been above 50. It is evident that the inclusion of the socio-economic characteristics of such young children or young wives in with these much older and different groups would reduce the data quality of the older group. Also, of course, the true number of children, wives, and householder-spouse families was somewhat reduced by these mistakes. Because this error is numerically fairly small, it can't have had much impact on data quality except in the very oldest population groups. Although there is no straightforward way to eliminate these cases, a way was found to minimize this problem. In 1980 our allocation subroutine for the age of father/mothers essentially replaced their unknown age with the age of the previously reported father/mother. Problems arose when there was a significant difference in the age of the householder in the two households. For instance, the previous householder might have been 45 and had a 70 year-old parent living with them. The next household, which required an allocated age, might have a 60 year-old householder. Our edit would give that 60 year-old a 70 year-old parent. Our later tests for data consistency often would not have rejected such cases and so needlessly unusual households were created.

This shortcoming of the edit procedures was eliminated by restructuring the matrices to store and assign the age difference between the householder and parent (rather than the parent's exact age). This has the effect of maintaining reasonable ages within each household.

Conclusion

This paper has focused on several methods by which both the design of the age question and the actual edit specifications could be improved. The age data for some elderly groups have been seen to be somewhat inadequate for any exhaustive analyses. This is one reasons it is so difficult to obtain irrefutable research results about the characteristics of the very old. It is important to view this work in its proper context. It only addresses some aspects of the quality of the age data for the enumerated population. The extent to which the 1990 census can completely enumerate the population, for instance, is far more important to the quality of the nation's data.

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CAPTURING THE FULL RANGE OF PHYSICAL FUNCTIONING IN OLDER POPULATIONS

Jack M. Guralnik, National Institute on Aging

With the increase in research on aging, the use of measures of physical functioning has become quite common. These measures have a long history, being originally developed to aid in the clinical evaluation of seriously disabled individuals, particularly those residing in nursing homes. In a recent publication, Feinstein and colleagues identified 43 different published indexes which assess the activities of daily living (1). The first of these, published in 1935, dealt with the evaluation of crippled children (2). The first index they found which specifically dealt with aging was published in 1957 by Moskowitz and McCann (3). In the recent past, the use of measures of physical functioning in aging research has been extended in two major ways. First, the use of these measures has gone beyond the nursing home and rehabilitation department and has now entered the community at large. Second, their application has broadened from their initial use as a clinical tool to their use in survey and epidemiologic research. Measures of physical functioning are now part of many of the major national surveys conducted by the National Center for Health Statistics (NCHS) and are being considered for inclusion in the 1990 census.

Empirically, there is clear evidence that physical functioning, or functional disability, is an important variable to include in aging research. In prospective studies, poor physical functioning has been predictive of future declines in functioning (4), need for institutionalization (5,6) and death, in both those living in the community (7,8) and those already institutionalized (9). In the Established Populations for the Epidemiologic Study of the Elderly (EPESE), funded by the National Institute on Aging, it was found that after age, the strongest predictor of mortality was a poor score on any one of several indices of physical functioning (10). In addition to the evidence that one's level of physical functioning is a predictor of many important outcomes, there are good theoretical reasons to recommend these measures in the evaluation of older persons. In describing levels of ability and disability, physical functioning assessment serves as an indicator of the overall impact of multiple diseases on an older individual. Additionally, these measures may also provide a means to evaluate overall health status and quality of life. There is much interest in studying good health among the elderly, which might potentially be identified by assessing higher levels of functioning.

Once we decide it is important to measure physical functioning, it is necessary to operationalize this concept through the use of some assessment instrument. The difficulties in measuring functional status can be appreciated by comparing it to the kind of measurement we usually do in clinical practice or research, such as assessing weight, serum cholesterol or even smoking history. These are unidimensional concepts and are relatively simple compared to measuring functioning. Physical functioning is clearly only one dimension within overall functioning, which some investigators divide into four domains: physical, cognitive, emotional or psychological and social. Even within the realm of physical functioning there may be multiple domains, with possible stratification into upper and lower body function or large motor and small motor function.

As physical functioning assessment has been more widely applied, numerous instruments have been developed and a variety of methodologic problems have become apparent to those working with these instruments. The purpose of this paper is not to review this wide range of available instruments. It will instead discuss selected methodologic issues which should be considered by those employing these measures in research settings. Issues to be discussed include [1] validity, [2] the measurement of change, [3] the aggregation of individual items into an index, [4] assessing the full range of functioning and [5] the need to evaluate the relationship of physical functioning measures to more conventional measures of disease.

Validity

Most instruments used to assess physical functioning rely on self-report or proxy-report. Evaluation of the validity of these instruments is important in attempting to understand what they are truly measuring, yet has received too little attention. There are a variety of ways to assess validity (11), although the ultimate test of validity, criterion-related validity, comes from comparing one's measure with a previously validated measure, a so-called "gold-standard." This gold-standard does not exist for physical functioning, so other approaches to validity testing must be applied. One approach has been to correlate self-reported functional status with assessments made by an outside observer, such as a physician or other health care provider. Since this outside observation may in itself be fallible, this is not strictly criterion-related validity, but is instead considered to be construct validity, which evaluates the association of different measures of the same construct. Construct validity is said to be high if the measurement of interest has a high correlation with those measures hypothesized to be related and a low correlation with those measures hypothesized to be unrelated. The construct validity of self-reported functioning has been studied by correlating it with both the global assessment of a caregiver (12,13) and with the responses of a caregiver to the identical functional assessment items (14).

Another approach to evaluating self-report of functioning is through the use of formal objective tests of functional performance. In several areas of functioning there are well-established ways of obtaining information through both these means. A study participant can be asked to rate his or her vision, hearing or memory. Validation of these self-reports can then be made through the use of visual acuity testing, audiometry and mental status testing. In the area of physical functioning, little work has been done using this approach to validation. In the evaluation of 776 participants in the Massachusetts Health Care Panel Study, Jette and Branch found self-reported physical functioning to be strongly related to objective tests of musculoskeletal and visual impairment (15).

In addition to their use in validation studies, performance-based instruments may also come to serve as valuable assessment tools in themselves. An important unanswered question is how much additional information is provided by objective measures of physical performance in terms of both describing an older individual and predicting important health outcomes. Jette and Branch make the point that the basic kind of objective performance tests which are available actually assess impairment, as defined by WHO as a loss of physiological or anatomical structure or function (15). Self-report of functioning, for instance ADL's such as dressing or eating, or IADL's such as shopping or cooking, are measures of disability, defined as a restriction in an individuals functional performance which results from an impairment. The complex interaction of impairment and disability in older persons will likely prove to be a fruitful area of investigation. Of note is that both the upcoming Third National Health and Nutrition Examination Survey and the next follow-up examination in the EPESE will contain objective measures which assess gait, strength and balance.

Change

In attempting to understand the dynamic process of aging, there is a potential to learn a great deal by following change over time. Among the most important areas for which an understanding of change would seem important are the various domains of functioning. The use of change in our daily lives seems so simple, for example asking someone if they are better, worse or the same as yesterday, that the difficult methodologic problems encountered in the assessment of change are completely unexpected. Many of these problems were first encountered by those evaluating repeated longitudinal measures of blood pressure (16).

The evaluation of change is very closed tied to the reliability of the assessment instrument being employed. Reliability can be thought of as the ability of an instrument to obtain the same result in the absence of real change, and it, like validity, has not been adequately evaluated for the instruments we currently employ. In the EPESE study, a high proportion of individuals showed changes in their scores on three instruments which assess physical functioning (17). These changes were in the direction of improvement as well as decline and occurred at both one and two years after the baseline evaluation. With little information on the reliability of the instruments, it is difficult to understand how much of this change is real and how much is related to the unreliability of the instrument.

It has been proposed by Guyatt and colleagues that, in addition to being reliable and valid, instruments being employed to measure change in individuals over time must also be evaluated for their ability to detect minimal clinically important differences, a property they term responsiveness (18). An instrument which is reliable is not necessarily responsive to change and an instrument which is very responsive to change may be not be reliable. Little methodologic work has been done in this area. In a review of 145 measures of health status used to assess older persons, only 10 were found to have some information related to sensitivity to change (19). In recent work using health status instruments, which are not limited to physical functioning but generally include a variety of domains of functioning, there have been mixed results in evaluations of the ability of these instruments to identify change. The Sickness Impact Profile (SIP) was used to evaluate change in rheumatoid arthritis patients by comparing it with clinical changes agreed on by both clinician and patient and with several clinical disease indicators (20). In this study, the SIP was found to be relatively insensitive to change within individuals. In another study, MacKenzie and colleagues administered the SIP to hospitalized patients (21). They found that it was somewhat sensitive to deterioration but not sensitive to improvement and concluded that this instrument may have limited usefulness in following individuals over time. Finally, in an assessment of another health status instrument, the McMaster Health Index Questionnaire, it was found that scores on the physical function component were sensitive to the improvements observed in patients attending a physiotherapy clinic (19).

In evaluating change as either an independent or dependent variable in analytic studies there is a great temptation to use the raw change score, which is simply score at time 2 minus score at time 1. Seriously biased findings can result from this approach, however, and the use of change in analytic studies must be approached with extreme caution. In a paper written in 1970 by the well-known psychometrician Cronbach, he warned (22), "Raw change scores formed by subtracting pretest scores from posttest scores lead to fallacious conclusions, primarily because such scores are related to any random error of measurement. Although the unsuitability of such scores has long been discussed, they are still employed, even by some otherwise sophisticated investigators." Raw change scores are very much affected by regression to the mean, which may be attributed to both the inherent variation of the phenomenon being measured and the variability (unreliability) of the measurement instrument itself (23). Methods have been developed to reduce the bias from regression to the mean in the study of blood pressure change (16,24), and hopefully these can be adapted for use with scales of physical functioning. It should be evident from the above discussion that a great deal of methodologic work remains to be done if we are to reap the potential benefits of studying change in physical functioning in older persons.

Aggregation

One of the major pitfalls involved in the use of any instrument whose purpose is to comprehensively evaluate a particular dimension is the problem of scale construction. If our goal is to go beyond the simple identification of those who are disabled and instead to characterize all members of a cohort along a comprehensive scale of functioning, then it is necessary to incorporate information from a number of different questionnaire or examination items into this scale. Interestingly, the techniques for scale construction have been developed much more fully in the social sciences than in epidemiology, where investigators have tended to use either dichotomous variables, such as vital status or the presence of a disease, or very simply constructed scales.

In an attempt to aggregate appropriate items into a scale, researchers faced with long lists of questionnaire items from which to select have turned to techniques such as factor analysis and cluster analysis. Even after appropriate items are aggregated, one is still faced with the task of developing a method of scoring to create a summary measure. This whole process of scale construction can be a difficult and laborious task. The various methodologies to evaluate scale validity and reliability will not be discussed here, but it is important to note that the more rigorous we are in constructing a scale, the more powerful and useful an instrument we will have.

The following illustration will illustrates some of the difficulties and choices which must be made in scale construction. The Supplement on Aging was a supplement to the 1984 Health Interview Survey (25). It takes a very comprehensive approach to physical functioning, and covers the full spectrum from activities of daily living, such as bathing and dressing, to items which query vigorous exercise. The range of items in this questionnaire includes: activities of daily living, instrumental activities of daily living (preparing meals, shopping, managing money, using the telephone and doing light and heavy housework), walking 10 steps, walking one-quarter mile, standing, sitting, crouching, reaching and grasping, lifting 10 and 25 pounds and finally, questions assessing activity and exercise.

It is obvious that if one were to do analyses using each of the preceding questions individually, it would be an unwieldy and unproductive task. A scale summarizing the information on physical functioning provided by this instrument would be of tremendous utility in analytic work on this cohort. The first step in scale construction would be to aggregate questions which measure a single dimension. It is very possible that some of the items in this list will drop out during this process. For instance, it is likely that those questions on managing money and using the telephone are more related to cognitive than physical functioning and should not be included. Since the response categories are not identical for all questions, the final task would be to develop an appropriate method of scoring individual items so a summary measure can be calculated.

There are obviously many choices to be made in the construction of scales of functioning. There has been much debate over whether the final scales we create should be global scales or component measures. The global scale is an overall summary measure of functioning or health status and has been compared to a single measure of the economy, such as the gross national product. Those opposing the use of global or multidimensional scales feel that a real effort should be made to identify and score discrete dimensions; that it would, for example, be inappropriate to aggregate scores on different types of functioning and that an appropriate weighting scheme for doing this type of aggregation does not exist.

The Full Range of Functioning

In certain types of aging research, there is good reason to attempt to characterize older persons along the full spectrum of functioning and not just the end of the spectrum that represents serious disability. As stated earlier, many of the instruments in use in aging research were developed for patients in nursing homes. In the community, the majority of older persons do not have a major disability. These community dwelling elders, however, do show a range of health status, vitality and functional abilities which, if measured, can provide us with much valuable information.

There are substantial practical problems, however, in actually measuring this full spectrum of functioning. In the EPESE baseline evaluation of persons aged 65 and older, about half of all respondents had no difficulty performing the two most difficult items queried, pulling or pushing a large object like a living room chair and stooping, crouching or kneeling (26). Using these items individually, we are unable to differentiate the entire top half of the spectrum of functioning. It might be possible to do a better job of assessing the full range of functioning by adding more difficult items to the questionnaire and also by developing a good way of aggregating available items to form a summary measure. This was done in the Health Assessment Questionnaire, which was developed at the Stanford Arthritis Center (27). Its disability domain is worth examining because it is an example of an instrument which attempts to be a comprehensive measure of functioning and which has undergone much methodological work. Many of the components represent activities of daily living, but certain components contain questions which evaluate more difficult activities such as reaching and getting down a 5 pound object, opening car doors, running errands and shopping and doing chores such as vacuuming and yardwork. When the Health Assessment Questionnaire was applied to a clinical sample of patients with rheumatoid arthritis, the sample was well distributed along the range of all possible scores (28). The HANES I Epidemiologic Followup Study conducted by NCHS has nearly the same items as in this scale, and almost identical scoring can be accomplished. The poor scores seen in the clinical population are much less common in this representative community sample, even in the oldest age groups, and most subjects still have perfect or nearly perfect scores. Using this scale, therefore, it is possible to characterize quite well those with moderate to severe problems, but we are still not able to disentangle the large group with minimal or no physical dysfunction. We are, for instance, not able to identify from these distributions those elders having the highest levels of physical functioning. Clearly, the challenge remains to characterize community dwelling older persons along the full spectrum of physical functioning.

Associated Diseases

The final topic for consideration is the relationship of specific diseases to disability. There are many advantages in aging research to temporarily suspend the medical model of disease, in which we deal with one disease at a time, in order to obtain a broader view of such areas as functioning, overall health status and quality of life. There is certainly much valuable epidemiology which can be done on the distribution, determinants and outcomes of poor physical functioning in older persons. However, most of what we know about prevention and treatment is related to specific diseases and we must swing full circle and eventually come back to the diseases responsible for dysfunction if we are to develop successful interventions.

The knowledge in this area is relatively scant at this time. NCHS frequently publishes data on the percentage of disability in persons with various diseases, but these data do not tell us whether or not the disease itself was responsible for the disability. A more valuable approach is to start with those who are disabled and determine the relative importance of one or even multiple diseases to their disability. This is probably quite difficult to do well, but it would allow for a very valuable determination, that of the attributable risk of specific diseases for population disability.

In understanding this area, it may be helpful to consider the theoretical construct of a pathway which goes from disease to decreased physical functioning to loss of independence to death. There are certainly diseases for which this pathway is followed, but others which do not follow it. A number of important issues in aging, for instance the controversy over the future compression of morbidity, would be better understood if we had good information on how this pathway functions for important diseases.

Some examples of this are worth considering. Coronary heart disease is a frequent cause of decreased physical functioning and loss of independence in those who eventually die from it. Cancer, on the other hand, may have no associated loss of functioning until a very short time prior to death. Arthritis may be the most important cause of dysfunction and loss of independence in older persons but may only rarely be associated with death. Finally, there are other domains of functioning outside the physical, and Alzheimer's disease may lead to a severe loss of independence and death without affecting physical functioning.

In concluding, it is hoped that this review does not leave the impression that the problems of measuring physical functioning are overwhelming. There are areas in this field which need careful methodological attention and important gaps in our knowledge, but these can be overcome. The goal should be to develop better assessment instruments, which have good reliability and validity and can assess the full range of functioning, to accumulate experience in assessing objective measures of functioning and to develop more sophisticated approaches in following change over time and in relating dysfunction to specific disease states. If this can be done, measures of physical functioning will continue to serve as important tools in aging research.

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ASSESSING CHANGE IN COGNITIVE FUNCTION IN COMMUNITY POPULATIONS OF OLDER ADULTS

Denis A. Evans, Paul A. Scherr, Nancy R. Cook, Marilyn S. Albert, and H. Harris Funkenstein, Channing Laboratory and Division of Neurology, Department of Medicine, Brigham and Women's Hospital, Departments of Psychiatry and Neurology, Massachusetts General Hospital, and the Departments of Medicine, Psychiatry and Neurology, Harvard Medical School.

Cognitive impairment is relatively common among those in the oldest age groups, and has a large impact on quality of life. It has not, however, been subjected to the same intensive epidemiologic investigation as have such common chronic diseases as coronary heart disease, stroke, or chronic lung disease. As the number of persons in these age groups continues to grow, it seems very likely that this major health problem will receive increasing attention.

Much of our current information concerning cognitive impairment in older persons comes from studies of patients admitted to chronic-care institutions, tertiary medical centers or psychiatric hospitals, or from patients referred for evaluation as outpatients. Such studies provide valuable data, but also have limitations because of the special nature of the populations investigated. Such patients may be selected according to a number of factors, including recognition of the problem by someone close to the individual, access to medical care, socioeconomic status, severity of the impairment, the presence of atypical clinical features, and the interests and abilities of the institution. Thus, studies of institutional groups do not necessarily lead to accurate conclusions regarding rates of impairment or the conditions responsible for impairment in free-living populations. Further, in analytic studies comparing the occurrence of possible risk factors among hospitalized persons with Alzheimer's disease to the occurrence of such risk factors among unaffected individuals, the use of hospital controls may pose considerable difficulty. Since the factors leading to hospitalization at a particular facility may be very different for different disease categories, patients with dementia may be drawn from different segments of the population than are patients with other diagnoses.

Community-based studies offer possible solutions to some of these problems, but also present certain challenges of their own which must be overcome if such studies are to be successful: Only fairly common conditions can be studied. Community-based studies are usually expensive and time-consuming even for relatively common conditions such as dementia. The assessment techniques that can be used in the community are usually limited, compared to those that can be applied in institutional settings. At the same time, the demands on these assessment techniques can be great, since in community-based studies of most conditions, mild, early cases of disease which may be difficult to distinguish from being unaffected are typically much more common than advanced disease. Community-based studies demand extensive organizational efforts, and, in general, it is more difficult to attain high rates of participation for these studies than it is for studies involving individuals who have come to an institution or provider seeking help. Another problem is that cognitive impairment is a somewhat sensitive topic, especially among individuals who may be afraid that they are either experiencing such impairment or may experience it in the near future. This sensitivity places demands on the design of assessment instruments and has the potential to adversely affect participation rates.

Despite these difficulties, investigations of cognitive impairment probably will include an increasing number of studies of geographically-defined communities or other large, free-living populations, and it seems appropriate to consider several choices facing designers of such studies. Four areas of practical study design appear to warrant special attention in community-based studies of cognitive impairment. Difficult choices must be made in each of these areas.

The first area is a difficult choice of whether to attempt diagnosis of the clinical conditions responsible for cognitive impairment or to employ only a more general measure of impairment. Clinical diagnosis adds very valuable information and aids effective communication of results because it corresponds to the way the subject area is usually considered by medical personnel. Diagnosis of specific conditions accounting for impairment is difficult, time consuming, and requires highly-skilled medical personnel. Thus it is difficult to apply to large numbers of persons in community settings.

The second area, closely related to the previous one, is whether to employ a single type of evaluation for cognitive impairment or to use a multi-staged approach. For attempting clinical diagnosis in a community setting, a two-stage procedure can be an efficient allocation of resources. The first stage consists of a screening or sampling instrument administered to the full age-eligible population which serves to crudely categorize individuals into strata according to level of cognitive function. The second stage consists of more detailed clinical evaluation. Since measures suitable for population screening for cognitive impairment have imperfect sensitivity, all strata of performance on the screening instrument should be sampled for clinical evaluation if descriptive statistics are to be refered back to the community population, for example, prevalence of specific disease entities such as Alzheimer's disease.

Our present studies of cognitive function in a defined community employ a two-stage procedure. Brief performance tests of certain areas of cognitive function were included in a population survey of all participating community resident over 65 years of age. Among these tests were immediate and delayed recall of a very brief, three-sentence story. Participants were divided into three groups according to their performance on this test and individuals from each of the groups were selected for clinical evaluation, sampling most heavily from the poor performance group. Selection from these performance groups was designed both to allow the results from the sample to be referable to the community population and to generate a cohort of affected individuals and a cohort of unaffected individuals for further study.

The third area is the choice of neurologic and neuropsychologic instruments and of a scheme of classifying individuals according to diagnostic categories if clinical evaluation is employed. Structured instruments are usually preferred to unstructured ones to reduce observer bias, and performance testing of areas of neuropsychologic function is probably the most widely accepted means of characterizing cognitive deficits. Many existing instruments in this area, however, are either based on observer opinion or were designed for use in clinical situations rather than in large community populations.

In designing the community-based studies of cognitive function currently being conducted by our group, for example, we thought that there were strong advantages to performance testing of specific areas of cognitive function and to using structured means of gathering and recording examination and questionnaire data. The decision to use such measures, however, required a substantial amount of adaptation of existing measures and, in some cases, creation of new ones. The final form of the instruments we used for screening in the general population was strongly influenced by pretesting in a neighboring community. This pretesting was very valuable both in selecting the brief performance tests that were used to characterize cognitive function at the population survey and in developing interviewer training methods.

The clinical evaluation included neuropsychological testing, neurological examination, brief psychiatric evaluation, laboratory evaluation, brief review of the medical history, and interview of a significant other individual for each participant. All prescription and over-the-counter medications used during the previous two weeks were identified. Each clinical evaluation required, on average, approximately two and one-half hours. The examiners were blinded to the subjects' performance on the population survey cognitive testing. To enhance participation, except for cranial computed tomographic (CT) examinations, the evaluations were carried out in the community.

As with the population survey measures, most components of this clinical evaluation procedure also required substantial design effort. Neuropsychologic performance testing was more detailed than the brief tests used in the community. Tests had to be chosen to address the areas of most relevance to cognitive impairment among older persons, to be acceptable to participants both in terms of duration of the evaluation and content of the tests, and to reflect the range of normal and impaired function anticipated in a free-living population. The functional areas tested included three tests of memory including a delayed recognition memory span test that required the participant to recall the spatial arrangement of an increasing series of disks on a checkerboard surface, a matching form of the Benton Visual Retention Test, and a short story recall test identical to that used in the population survey. Other areas of cortical function tested included confrontation naming, visuospatial ability, abstraction, and set maintenance. The test of confrontation naming consisted of 15 line drawings of objects taken from the Boston Naming Test. Tests of visuospatial ability included a test of ability to copy geometric figures and a task requiring matching of simple geometric figures. Abstraction was assessed by the ability to identify similarities and differences among sets of geometric figures. The test of set maintenance required the participant to copy a sawtooth design of alternating triangles and squares, and then continue the alternating pattern across the page. Attention was formally assessed by an auditory vigilance task in which the participant was asked to listen to a recorded series of letters and to identify every instance of the letter "A" being spoken.

A structured neurological examination was designed with clearly defined scoring criteria. It was similar to a comprehensive neurological examination in clinical practice, but also included alternate and sequenced hand positions, finger tapping speed and a brief assessment of language and praxis. A major purpose of the neurological examination component was to recognize the presence of conditions other than Alzheimer´s disease that might result in cognitive impairment, such as strokes, Parkinson´s disease, and hydrocephalus.

To enhance cooperation, the number of examiners with whom each participant interacted was restricted. Therefore, the neurologist also conducted the brief psychiatric evaluation. Its major purpose was to recognize the presence of psychiatric disorders that might produce cognitive impairment in older persons. Emphasis was placed on the identification of depression and major thought disorders. The depression section of the Schedule for the Affective Disorders and Schizophrenia--Lifetime version (SADS-L) was used to elicit information concerning both major and minor depressive symptoms. In addition, the Brief Psychiatric Rating Scale of Overall and Gorham was completed by the examiner.

Several points about the design of the classification scheme deserve discussion to illustrate issues in this area. From the results of the clinical evaluation, each individual was classified in two ways: First, according to the severity of any cognitive impairment as none, borderline, mild, moderate, or severe; and, second, according to the condition responsible for the impairment, with each of a series of diagnoses rated as absent, possible, probable, or highly probable. Diagnoses were not regarded as mutually exclusive. These parallel classifications were used to minimize confusion between the severity of impairment and the evaluator´s degree of confidence in the diagnosis.

The diagnostic criteria for Alzheimer´s disease were in general agreement with those for primary degenerative dementia specified in the third edition of the Diagnostic and Statistical Manual of Mental Disorders of the American Psychiatric Association[1] (DSM III criteria) as well as the criteria for the clinical diagnosis of Alzheimer´s disease developed by the joint work group of the National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer´s Disease and Related Disorders Association[2] (NINCDS-ADRDA criteria). Three adaptations of these criteria were required. First, DSM III criteria require that there be "A loss of intellectual abilities sufficient to interfere with social or occupational functioning."[1] Measures of occupational status and social function were included in our study, but were not directly used in the disease definition because of our concern that impairment in these functions could not be uniformly applied as a disease criterion in a population of older individuals of both sexes with wide variation in both social networks and current and lifetime occupational backgrounds. Instead, this concept was addressed by establishing the presence of cognitive impairment of sufficient magnitude that interference with these functions could be reasonably assumed. Second, the NINCDS-ADRDA criteria use absence of other diagnoses of dementing illness in determining probability of Alzheimer´s disease. As noted earlier, however, we were not comfortable with assuming that disease categories are mutually exclusive. Third, in our study we designated highly probable and probable categories of Alzheimer´s disease both of which would be included in the probable Alzheimer´s disease category of the NINCDS-ADRDA criteria.

The fourth broad area is whether to use change in cognitive function as a variable of interest. One reason to strongly consider such an approach is that detection of decline in cognitive function may permit reliable ascertainment of incident occurrence of dementing conditions such as Alzheimer´s disease. This would have value for both descriptive and analytic purposes. For example, accurate determination of rates of incident disease would be useful for describing the public health impact of the condition. As in studies of other chronic diseases, using incident disease as an outcome is effective in clarifying the temporal relationships between possible risk factors and the disease.

For accurate description of change in cognitive function from sequential measurements, it is necessary to distinguish real change from random variation in the measure of cognitive function. However, little is known at the present time about the short term variability (or test-retest reliability) of most measures of cognitive function suitable for use in community populations.

With regard to the use of change in cognitive function as an outcome variable, perhaps the largest concern is to avoid bias in assessing the relationship between an exposure measurement and change in cognitive function. Therefore, our concern with assessing variance components so as to distinguish real variation from random variability is probably less than in the previous situation, unless there is good reason to suspect that variance in cognitive function is not randomly distributed among the exposure groups.

One complex and difficult issue is how to approach regression toward the mean in serial measures of cognitive function. A particularly difficult question is whether, in an attempt to adjust for regression toward the mean, initial level of cognitive function should, in some way, be included as an independent variable in models with change in cognitive function as the outcome. One might argue that the inclusion of initial level will lessen the effects of regression toward the mean, but carries the risk of introducing bias since exposure groups may well differ systematically with regard to initial level of cognitive function. The effect of omitting such adjustment should be to give unbiased but imprecise estimates of the relation between exposure and change in cognitive function. One route which may warrant exploration is the use of classical autoregressive models as employed in time series analysis in an attempt to reach more precise estimates.

A second analytic issue one may confront is the so called "horse racing effect" described by Richard Peto and colleagues in analyses of serial measures of pulmonary function, particularly the forced expiratory volume or FEV.[3] They were studying a disease process which began early in life in a group of middle aged men. Thus, those men who had been experiencing decline in pulmonary function prior to the beginning of the study had both lower levels of FEV at the initial study examination and the expectation of continued decline in FEV since they had reached the low initial levels through a pre-existing disease process which would continue during the study period. Peto and colleagues raised concern that, in this study and perhaps in other longitudinal studies, this relation between level and change can lead to an observed relation with change in level for any exposure related to initial level, even when the relation of the exposure variable is clearly non-causal, as for example when the relation is one of low initial level causing the alleged exposure. The extent to which this will be of concern in studies of cognitive function studies remains to be seen. There may be somewhat less cause for concern than in investigations of lung function since, a lower age limit of 65 years, frequently used in studies of cognitive function among older persons, appears to be lower than the age of onset of Alzheimer´s disease for the majority of affected individuals.

It seems likely that, over the next several years, community based studies of dementia will continue along the path followed in studying other common chronic conditions. There will likely be more emphasis on analytic as well as descriptive studies as specific etiologic hypotheses are investigated and as dementia is related to such possible outcomes as mortality, institutionalization, and hospitalization. Our ways of thinking about the condition may continue to become less like a single cause-single effect model and more like the multiple risk factor concepts employed in studying other chronic diseases. How successfully we will be in following this path may depend on our ability to solve a number of challenging, practical methodologic problems such as those noted.

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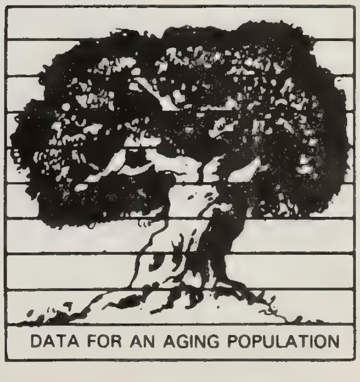
Session P

Experiences in Record Linkage


DATA FOR AN AGING POPULATION

TRACING EPIDEMIOLOGIC STUDY SUBJECTS TO DETERMINE VITAL STATUS

Dan J. Grauman, National Institutes of Health

INTRODUCTION

The task of ascertaining vital status is accomplished through systematic tracing efforts, some sequential and others concurrent. This presentation will be restricted to a review of the various tracing methods being utilized at the National Cancer Institute, a description of the record linkage considerations associated with some of the methods, and a brief description of the Tracing Management System (TMS), a computerized system which tracks the tracing activities. Cost of tracing will not be considered in this presentation, nor the relative merits of some methods versus others.

BACKGAROUND

The dictionary defines tracing as the act of "locating or discovering by searching or researching evidence". In fact, the word "tracing" has different meanings to different people. For example, when the National Cancer Institute solicited proposals from sources who could provide tracing services, responses were received from organizations such as detective and security agencies, who listed the types of equipment and methods available to them for "finding" people who do not wish to be found. Proposals of this type were received despite the fact that it was clearly explained that the vital status of study subjects was required for research purposes, not their apprehension.

Vital status determination is a critical component of epidemiologic studies. The type and amount of identifying information available for study subjects varies from study to study, as does the recency of last contact with subjects. These factors combined with the mobility of the U.S. population make the job of tracing study subjects a challenging one.

Between 30 and 60 epidemiologic studies are being conducted simultaneously at any given time within the Epidemiology and Biostatistics Program of the National Cancer Institute. Study populations range in size from 80 to 80,000. The endpoint for many of these studies is a statistical analysis of mortality, which requires ascertainment of the vital status of study subjects.

Let us assume that we are at a point in a retrospective epidemiologic study at which we can begin the tracing process. Typically, a computerized master data file is in place. This file contains study subject identification numbers and names, some demographic data such as date of birth, sex, race, Social Security number, and address at a given point in time. Note that not all of these variables are available for every study, and those that are available may be missing for a portion of the study population. Occupational history, military service history, and medical history may also be available.

FIRST LEVEL OF TRACING

The first level of tracing can be initiated with a minimal amount of demographic data. Social Security number and last name are sufficient for a Social Security Administration vital status search. Data tapes submitted by the National Cancer Institute are run against Social Security Administration files. A computer card indicating one of several match outcomes is produced for all study subjects except those still assumed living by the Social Security Administration. These results are then linked back to the study master file in preparation for the next step in the tracing process.

If first and last name plus month and year of birth are available, data can be submitted to the National Center for Health Statistics for matching against the National Death Index files, which contain all U.S. deaths from 1979 forward. Output from this match is received in the form of computerized lists and/or magnetic tapes. The relevant data can then be linked to the study master file.

Following are some of the outcome categories resulting from first level tracing:

Deaths

The National Death Index output includes death certificate number. This facilitates the process of requesting death certificates from state vital statistics offices. The Social Security Administration, on the other hand, provides a date of death and the name of a state, which could be the actual state of death or the state of last residence. Obtaining a death certificate in this case may not always be trivial.

Assumed Living

While individuals in this category are not directly identified by the Social Security Administration, their identity can be derived by default, as the individuals in all other categories are identified. Individuals in this category are assumed living as a result of their interaction with the Social Security Administration, namely by their paying into the Social Security system or deriving benefits from it.

Other Outcome Categories

Several other outcome categories make up the balance of a typical Social Security Administration output data file. Study subjects in these categories are the most interesting, since they generate the next level of tracing.

Status Unknown

The study subject in this category is not currently interacting with the Social Security system and no claim has been filed. A typical example of such a subject is a federal government employee who currently contributes to the Civil Service Retirement System rather than to Social Security.

Unmatched Study Cases

The Social Security number/name combination submitted does not match Social Security Administration files. It should be noted that the name submitted is matched against all names existing in the Social Security Administration file for that Social Security number.

Impossible Social Security Number

This is a very small outcome category of Social Security numbers that have not been established. Such a number is usually the product of an error in the abstracting or keying process.

SECOND LEVEL OF TRACING

Several possible alternatives are included in the second level of tracing. The alternative of choice is mostly dependent on the outcome of the first level of tracing. It should be noted that for those study subjects lacking the minimal demographic data previously described, this would actually be the first tracing phase.

The primary second level tracing methods are:

Credit Bureau Records

Sources include credit reporting system records

Motor Vehicle Bureau Records

Sources include driver´s license records and motor vehicle registration records

Publicly Available Records and Lists

Sources include telephone, city, criss-cross, Polk and other directories and lists

Other Resources and Sources

Sources include other miscellaneous resources such as post office inquiries, voter registration records, union or pension records, vital records, and personal interviews.

TRACING MANAGEMENT SYSTEM

As indicated in the introduction, many studies are ongoing at any point in time. Tracing activities for these studies are at various stages of progress, involve most, if not all, tracing methods previously discussed, and usually span the entire U.S.

This high volume of data necessitated the development of a comprehensive computer system that would organize and manage the information flow resulting from requests to trace study subjects. This system, known as the Tracing Management System (TMS) keeps track of the tracing requests, generates a standardized tracing log form for each study subject, and records dates of transmittal of forms to the tracing contractor and back again to the National Cancer Institute.

The input to the Tracing Management System consists of computer files derived from the study master file and arranged in accordance with strict specifications contained in a "Requestor´s Manual". These files are edited and re-edited by TMS. When the fully edited files are finally processed through TMS, tracing log forms are generated. These forms are distributed to the various contractors responsible for carrying out the specific tracing activities. This is the "log-out" procedure. Each form that is returned by the contractor is then "logged in" by the system, so that the location of any form can be ascertained at any point during the process.

Among the tracing methods discussed, two involve a substantial amount of record linkage, namely, credit bureaus and motor vehicle bureaus.

There are five major automated credit bureau networks covering the U.S. Some areas of the country are covered by just one of these networks, while other areas, especially large metropolitan areas, receive coverage from more than one network. When a study subject is traced by this method, one has the advantage of the wide geographic coverage, as well as the constant updating of these files by the credit bureaus. It should be noted that the only information sought by the National Cancer Institute is the most recent date on which credit activity took place, which generally serves as a good surrogate for last date known alive. No financial information is ever sought or received. There is ample legislation, such as the Fair Credit Reporting Act, which protects individuals′ rights in these matters. In fact, each inquiry of an individual′s credit file must be noted in that file.

Motor vehicle bureau files, although automated for many states, are somewhat more limited than credit bureau files. The area of coverage is limited to a state. Thus, a fairly accurate and recent address must be available in most cases. In addition, most computerized motor vehicle bureau systems match on a combination of SOUNDEX code, which requires full name (including full middle name) and date of birth. Hence, these data items must be readily available in order to attempt a computerized search. The optimum results can be obtained by a computerized search with human intervention in the form of an individual manually evaluating "close matches".

Driver′s license records and motor vehicle registration records are available in computerized form. The latter are not very reliable, since the driver of a vehicle may often be someone other than its owner. Driver′s license records are the better choice, although these are renewed every four years in many states, and may, therefore, not necessarily represent the most current information.

Publicly available records and lists are generally not computerized, with one notable exception - the telephone directory assistance lists. These are of primary interest when the endpoint is a telephone number (e.g., to conduct a telephone interview). Accurate name and address are required for successful use of these files.

The types of files available in the "other resources and sources" category are rarely computerized.

CONCLUSION

A brief review has been presented of some of the record linkage considerations which are associated with tracing epidemiologic study subjects to determine vital status. In summary, record linkage takes place at several levels. There is the record linkage that occurs between the study master file and the Tracing Management System, which tracks all tracing activities. Then there is the record linkage between the study master file and the tracing resource, i.e., Social Security Administration, National Death Index, credit bureau, motor vehicle bureau, telephone directory assistance. Finally, there is a tremendous amount of record linkage occurring within the tracing resource, e.g., several files are accessed within the Social Security Administration system for the purpose of obtaining the vital status outcome which is ultimately reported.

It is hoped that this overview has provided some appreciation for tracing, a very important phase of the epidemiologic study which usually receives little attention when the results of the study are presented.

LINKAGE OF HEALTH SURVEYS TO MEDICARE SERVICE USE FILES

Kenneth G. Manton, Ph.D.
Duke University

(Not available for publication)

NHANES I EPIDEMIOLOGIC FOLLOWUP STUDY: TRACING EXPERIENCES

Diane M. Cadell, David Cantor, and Kathleen Parkes, Westat, Inc.;
Helen E. Barbano, National Center for Health Statistics

■ Background

The First National Health and Nutrition Examination Survey (NHANES I) was conducted between 1971 and 1975. The NHANES I study population was defined as the civilian, noninstitutionalized population of persons ages 1 to 74 who resided in the coterminous United States. Study participants (32,331) received a medical examination and questionnaires covering a variety of topics. In the late 1970's a decision was made to conduct a longitudinal study of a subgroup of study participants (i.e., those participants receiving the exam who were 25-74 years of age at the time of the NHANES I exam). Under the direction of the National Center for Health Statistics (NCHS) and the National Institute on Aging (NIA), Westat, Inc., conducted the NHANES I Initial Epidemiologic Followup between 1980 and 1984. The purpose of this followup was to provide continuing information on participants' health status. The sample consisted of 14,407 persons, of whom approximately 93% were eventually traced, i.e., vital status was determined. The majority of tracing was completed prior to interviewing which was conducted between 1982 and 1984.

During 1985 and 1986 Westat conducted a Continued Followup of the Elderly (i.e., all persons at least 55 years of age at the time of the exam). The sample consisted of 3,978 study participants of whom approximately 96% were traced.

This paper describes the methods used to trace this elder cohort in the NHANES I Continued Epidemiologic Followup of the Elderly and the criteria used to determine whether or not the person traced was a study subject.

■ Overview of Tracing Procedures

When developing a tracing strategy, it is important to take the following into consideration:

1. Which data items are available for the study population? Tracing sources used will depend on which data items are available (e.g., Social Security number is essential for submission to the Social Security Administration).

2. How much time is available to trace study subjects? If time is limited, tracing steps may need to be done simultaneously. Tracing sources which have a slower turnaround time, such as requests for vital statistics searches from departments of vital statistics, should be started early.

3. How much money is available? Some tracing methods produce a high yield but are much more expensive than others, e.g., criss-cross directory searches.

4. Which tracing methods have previously been tried on study subjects? For the NHANES I Continued Followup of the Elderly, study subjects had undergone in-depth tracing during the Inital Followup survey and many methods used to trace subjects who were lost at Initial Followup were not repeated in the Continued Followup.

At the start of the Continued Followup Study the cohort was divided into two groups: those subjects with previously-confirmed vital status on the Initial Followup; and those who were lost to followup. These two groups determined the type and sequence of tracing methods used to locate a subject. During the Initial Followup, it became apparent that certain data items were valuable for tracing. Therefore, during that survey, data items useful for future followups were collected. These included: (1) a tracing reference, (2) subject Social Security number, (3) household enumeration (name, sex and age of all persons in household) and (4) father's surname, if female. The information was much less complete for subjects who were lost to followup on the Initial Followup since none of the above information had been gathered as part of the NHANES I examination. Therefore, secondary tracing sources not implemented in the Initial Followup and ongoing government sources were used to find these people.

Many tracing procedures were done simultaneously, as there was a limited tracing time and some methods, such as post office checks, took months to complete.

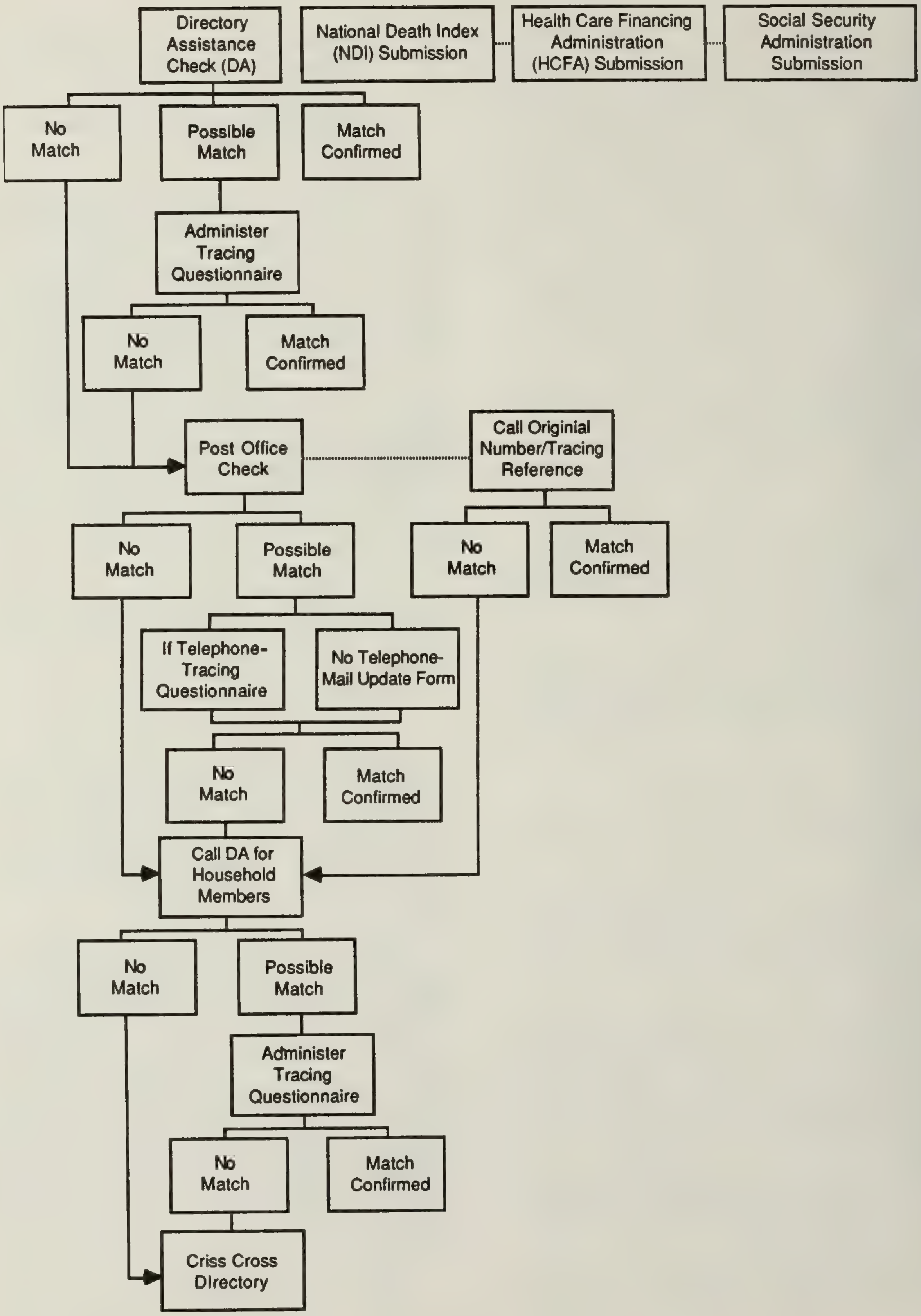
■ Methods Used to Trace Subjects with Previously Confirmed Vital Status at Initial Followup

An overview of the tracing methods used for subjects with previously confirmed vital status is shown in Figure 1. For these subjects, tracing staff called directory assistance in the residential area of the last known contact. A subject was considered found if there was a match on the first and last name and either: (1) the original address and phone number; (2) the original address and a new phone number; or (3) a new address and original phone number were given.

Persons who had the same first and last name but a different address and phone number were not considered found but were considered possible matches. For all possible matches, staff called and administered a tracing questionnaire to the person in question. The purpose of the tracing questionnaire was to verify the subject's identity, obtain address information on the subject or proxy (if appropriate), obtain death information if appropriate, and obtain a more current tracing reference. To verify the subject's identity, the respondent verified the subject's birthdate and the subject's address at the time of previous contact. If either the subject's address or birthdate did not verify, the interviewer asked about household composition at the time of the last contact (either at the date of exam or the date of Initial Followup).

Two out of three criteria had to match to consider the subject verified. Criteria for verification of the

Figure 1. NHANES I Continued Followup of the Elderly Tracing Methods for Subjects with Previously Confirmed Vital Status at Initial Followup (3,763)


Directory Assistance Check (DA)
National Death Index (NDI) Submission
Health Care Financing Administration (HCFA) Submission
Social Security Administration Submission
No Match
Possible Match
Match Confirmed
Administer Tracing Questionnaire
No Match
Match Confirmed
Post Office Check
Call Original Number/Tracing Reference
No Match
Possible Match
No Match
Match Confirmed
If Telephone-Tracing Questionnaire
No Telephone-Mail Update Form
No Match
Match Confirmed
Call DA for Household Members
No Match
Possible Match
Administer Tracing Questionnaire
No Match
Match Confirmed
Criss Cross Directory

birthdate were different depending on whether the subject or a proxy (in the case of an incapacitated or deceased subject) answered the question. Birthdate was considered verified if the day, month, and year of the birthdate matched exactly or, if the month and the day matched, the birth year could be plus or minus two years. If a proxy was answering the verification questions and birthdate was not known, the age of the subject had to be within a two-year range in either direction. If the proxy did not know the age, the interviewer requested a new proxy. Address at the time of last contact was considered verified if the street name, city, and state were the same as the address of record. Street number did not need to match. Household membership at the time of last contact was considered verified if the respondent recalled the name and relationship of at least one household member. (If the subject lived alone and that was reported, it was considered a match.)

The results of this initial directory assistance check yielded approximately 60% of the cases as confirmed match or possible match and 40% as nonmatched.

All nonmatches were submitted to the post office in the form of update requests which were grouped and sent to the postmaster at the zip code of the subjects' last known address. The postal service could (1) confirm that mail was still delivered to the address given, (2) provide a forwarding address, (3) provide death information, or (4) state that the respondent no longer received mail at the address. The post office checks yielded potential matches (i.e., a forwarding address, or deceased information) and nonmatches. If a telephone number could be secured (usually a new address was given), staff would administer a tracing questionnaire. If no phone number was available, the subject was sent a mail update return, which confirmed that the person was a study subject and requested an updated phone number. Since the post office check operation took about two months to complete, the next tracing step was started simultaneously.

Next, the staff called the tracing reference obtained during the Initial Followup for nonlocates. In many instances, the tracing reference would indicate that the subject was still at the same phone number. It appears that directory assistance information was not totally reliable, that is, many times directory assistance did not provide a number for the subject when in fact he/she was still at the same number. Once into the study, therefore, the original number was tried before actually contacting the tracing reference.

When collecting a tracing reference on the Initial Followup, field interviewers were instructed to probe for persons that were related to, but not living with, the respondent. Obtaining the name of someone who lived outside the household increased the probability that if the respondent moved, the tracing reference could still be found. Obtaining a relative was important because these individuals would be more likely to keep in touch with the respondent for his/her entire life. One exception to this was the use of older relatives, such as parents, who might die sooner than the subject. When obtaining information on a tracing reference, interviewers requested the name, address, telephone number, the name under which the phone number was listed and the relationship of the tracing reference to the subject.

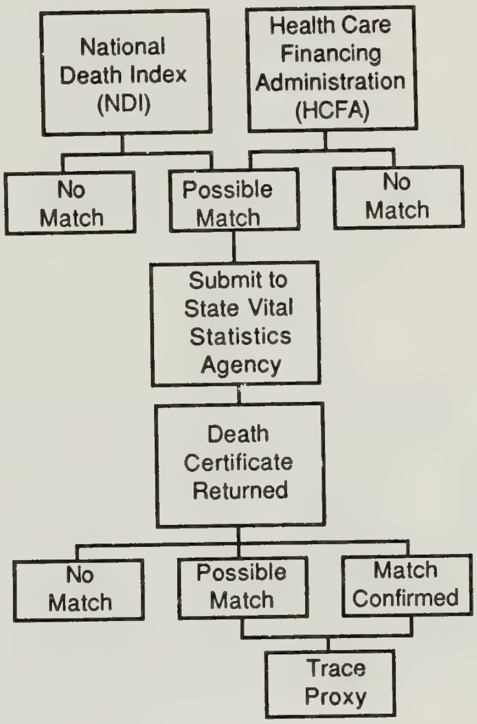
If all of these methods did not yield a confirmed match, the tracing staff next reviewed the Initial Followup household enumeration or the original 1971-1975 household enumeration for leads. The telephone tracers used household member names and employer names as leads.

During the tracing process, requests were routinely made to the National Death Index (NDI) and the Health Care Financing Administration (HCFA). One request was made to the Social Security Administration for information on all participants having a Social Security number.

- **Determining if the Subject Had Died Since Last Contact**

Both NDI and HCFA were good sources for confirming the deaths of subjects. Figure 2 provides an overview of the methods used to trace deceased subjects.

Figure 2. NHANES I Continued Followup of the Elderly Death Tracing


National Death Index (NDI)
Health Care Financing Administration (HCFA)
No Match
Possible Match
No Match
Submit to State Vital Statistics Agency
Death Certificate Returned
No Match
Possible Match
Match Confirmed
Trace Proxy

All persons in the sample except those whose deaths were previously confirmed by a death certificate were submitted to NDI periodically during the survey. When submitting to NDI, a user must have a first and last name for the subject and either a Social Security number, or a month and year of birth. NDI uses key items in the searching procedures to determine a possible match. Additional data items are on the NDI data set and can be compared with corresponding items on the record to see if they agree and disagree. The seven key matching items are: name -- first, last and middle initial; Social Security number; date of birth; father's surname (if female) and sex. Other variables valuable in assessing data include age at death, race, marital status, state of last known residence, and state of birth.

Westat could and did supply data to NDI on all variables except age at death for at least some of the subjects. NDI matching criteria were set up by taking different combinations of key variables such as Social Security number and last name. If NDI and Westat data matched on at least one criterion, the record was considered a possible match. In July 1985, the date of birth criteria were relaxed to enhance possible matches. Until that time, the criteria were exact month and year of birth. The new criteria included month of birth and plus or minus one year in birth year and a month and day match but no year match. From previous experience, it has been found that this type of leeway in year of birth is very necessary since often a respondent's answer to the year of birth is off by several years.

Once data was returned from NDI, staff ran the data through a computer matching program which ranked possible matches by assigning a score based on certain variable matches. The Westat program ranked on 8 variables and the score ranged from 0 to 999 points. Output was printed in reverse order, from highest to lowest rankings. The ranking variables were: sex; Social Security number; name (matching criteria were that the first and last name matched); birthdate (matching criteria were that month, day and year were an exact match or an exact match on month and year only); father's surname; race; state of residence and state of birth. Tracing personnel reviewed output in ranked order and reviewed records on a case-by-case basis. Generally, the supervisor would send for death certificates if most data items matched and date of death was after the date of last contact. Matches on date of birth were usually within a plus or minus two-year range. For females, personnel would look for a match on father's surname even if last name and marital status did not match. Of the 168 deaths identified through NDI and requested from states, 154 (92%) correct death certificates were received.

Another source for finding subjects who had died since last contact was submission of data to the Health Care Financing Administration (HCFA). NCHS made arrangements with HCFA, through the Bureau of Data Management and Strategy, to have subjects 65 years of age and older matched to their Medicare eligibility file. A data tape was submitted to HCFA containing all the study subjects except those known to be deceased and for whom a death certificate had been obtained. Those deceased for whom a death certificate had not been obtained were included, with the expectation of obtaining the state and date of death. Two files were submitted to HCFA: one contained subjects with Social Security numbers; the other contained subjects without Social Security numbers.

HCFA, in turn, prepared two separate files. One file contained all cases which matched on Social Security number. This data file contained the subject's name (first, middle initial, and last), sex, race, date of death if deceased, date of last claim, address at time of last claim, date of birth and Social Security number. Only the Social Security number was used in matching at HCFA. Tracing staff matched the data file provided by HCFA against the Westat file and checked the name, sex, race, and date of birth to make certain the Social Security number was for a study subject, not a spouse or other family member using the subject's Social Security number. (A matching problem encountered with HCFA as well as with other methods which match on Social Security number is that subjects sometimes give their spouse's Social Security number instead of their own.)

HCFA prepared another file for subjects without Social Security information. For this file, HCFA matched on the first six characters of first and last name, middle initial, date of birth and sex. Everyone on this file was considered a possible match.

If possible matches from either file identified a subject as deceased, a request for the death certificate was submitted to the state identified by HCFA as the state of death. Of 164 deaths identified this way and requested from the states, 145 (88%) correct death certificates were received.

Some death certificate requests were based on other sources of information, such as from a tracing reference or from speaking with the relative at the time of interview. In total, 334 such requests were submitted to states and 291 (87%) correct death certificates returned.

Sometimes tracing leads, for example, former neighbors of subjects, would report they thought the subject had died but didn't know the date of death. In these cases, state vital statistics agencies were contacted and asked to search for death certificates over a series of years. Twenty seven (27) such searches were requested and 12 (44%) were returned as correct death certificates.

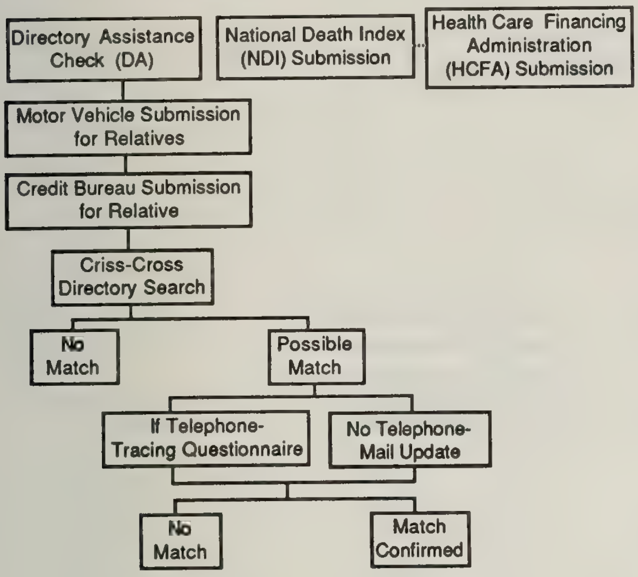
When a death certificate was returned, certificate information was matched against subject information. Eleven data items were reviewed. The first five items had to match. These were: name (first, middle initial and last); date of death (year could be off plus or minus two years if month and day matched); place of death; sex; and race. In addition, four of the six remaining criteria needed to match to consider the certificate found. These included date of birth (birth year could be off plus or minus two years if month and day matched), Social Security number, father's surname (females), address, place of birth, and spouse's name. If a death search had been completed, date and place of death would not be known and would, therefore, drop out of the criteria.

■ Methods Used to Trace Subjects Who Were Lost to Followup at Initial Followup

There were 215 subjects who were lost to followup at the time of Initial Followup. This group underwent a somewhat different tracing route. During the Initial Followup, all subjects underwent in-depth tracing. Tracing sources included directory assistance, post office, department of motor vehicles, department of vital statistics, social service agencies, HCFA, credit bureau, National Death Index, voter registration, and neighborhood tracing in the field. Because of this, many of the methods used to trace the subjects with previously confirmed vital status were not tried again. An overview of the tracing methods used to trace these lost to followup subjects is shown in Figure 3.

Directory assistance calls were made for all 215 subjects to determine whether they had returned to the area where they previously lived. Next, subject household enumerations from the NHANES I exam were reviewed, and names and birthdates of family members were keyed onto files. Where possible, tracers looked for younger male relatives and male spouses for female subjects. These relatives' names were checked through motor vehicle offices and credit bureaus. Neither tracing source was successful. Relatives' names for 32 subjects (78 relatives) were sent to motor vehicle offices and only one subject was found by this method. For credit bureau checks, relatives' names for 41 subjects (58 relatives) were sent, and no subjects were found.

Figure 3. NHANES I Continued Followup of the Elderly Tracing Methods for Subjects Lost to Followup at Initial Followup (215)


Directory Assistance Check (DA)
National Death Index (NDI) Submission
Health Care Financing Administration (HCFA) Submission
Motor Vehicle Submission for Relatives
Credit Bureau Submission for Relative
Criss-Cross Directory Search
No Match
Possible Match
If Telephone-Tracing Questionnaire
No Telephone-Mail Update
No Match
Match Confirmed

The most productive method used to find lost to followup subjects was criss-cross directory searches. When all of the tracing methods described above failed to find the subject, a group of tracers was sent to the Library of Congress to find additional leads in city and telephone directories. A "criss-cross" directory was used to locate residents living on the block where the subject was last known to reside.

Tracers used a variety of directories containing various pieces of data. Directories used contained residential listings by name, street address, or telephone number and included information about the household, such as household composition, renter vs. homeowner, name of employer, occupation, number of years at address, and number of years listed in the directory at the same address.

Tracers were instructed to look for the latest year of the directory available. If there were more than one type of directory available, tracers were instructed to choose the directory containing the most information about the household. Tracers were provided with ID number, subject name, original address, original telephone number, last date known alive, and a household enumeration.

The tracers were instructed to record information on the current resident at the address of interest and up to three neighbors. Tracers used the information in the directories to try to find long-time residents. This increased the chances that the person would be familiar with persons who might have moved in or out of the area some time in the past. If the block did not seem to exist anymore, or it seemed to be primarily a business district, the tracer recorded a name and phone number of a nearby store. In some cases, store owners/keepers were familiar with the residents of a block and could provide information on the subject.

Tracers recorded additional leads from the phone directory. Depending on the name, numbers were recorded that were listed under the same name and/or initials. If it were an extremely common name, two or three of the names were picked at random. The telephone directory lookup was discontinued after a while because the time spent did not justify the number of subjects found. The telephone tracers then called leads to inquire about the location of the subject.

- **Results**

Westat developed a tracing management system to monitor the tracing status as well as other variables for each study subject. One variable in the system is best tracing source. The best tracing source is defined as the first successful tracing source which leads to locating the subject. When reviewing these results, a few things should be kept in mind. First, there can be only one best tracing source per subject. Subjects were sometimes located by multiple actions because tracing methods were carried out simultaneously. In such cases, the method that produced the quickest result was credited. For example, if a post office check and a tracing reference call were performed at the same time, the tracing reference call, if successful, would be credited even if, two weeks later, a post office check was returned with updated information. Secondly, the order in which the methods were tried also affected results. Lastly, the number attributing various subject death-tracing methods such as NDI and HCFA to best tracing source is lower than the actual number of correct death certificates received. Table 1 provides information on the best tracing source.

Of the 3,763 subjects who had a previously confirmed vital status at Initial Followup, 3,695 (98.2%) were traced again. Directory assistance (60%) was the best tracing source by far. It should be remembered that this was actually the first tracing step and that this group had been interviewed in 1982-84, an average of two years before they were retraced. Calls to the original telephone number located 15% of the sample and calls to the tracing reference added another 12%. Of the 215 subjects who were lost to followup at the end of the Initial Followup, 109 (50.7%) were traced in the Continued Followup. The best tracing source for this group was criss-cross directory searches (36%), followed by information from NDI (24%) and original data (18%), i.e., the in-depth review of the tracing history from the Initial Followup for missed leads. Another good tracing source was HCFA (8%).

In summary, of the 5,677 subjects who were 55 years of age or older at the time of the NHANES I exam, over 98% were traced and vital status determined in either the Initial Followup or the Continued Followup.

This survey was jointly initiated by the National Institute on Aging and the National Center for Health Statistics, and has been developed and funded by the National Center for Health Statistics; National Institute on Aging; National Cancer Institute; National Heart, Lung, and Blood Institute; National Institute of Arthritis, Diabetes, and Digestive and Kidney Diseases; National Institute of Mental Health; National Institute of Alcohol Abuse and Alcoholism; National Institute of Allergy and Infectious Diseases; and National Institute of Child Health and Human Development. The field work was conducted by Westat, Inc., under contract No. 282-82-2111.

Table 1. Best Tracing Source[1]

	Vital Status at Initial Followup Previously Confirmed and Confirmed Continued Followup		Vital Status at Initial Followup Lost to Followup and Confirmed Continued Followup		Total	
Directory Assistance	2202	(59.6%)	3	(2.8%)	2205	(58.0%)
Original Data[2]	560	(15.2%)	20	(18.3%)	580	(15.2%)
Tracing Reference	450	(12.2%)	0	-	450	(11.8%)
Post Office	117	(3.2%)	1	(0.9%)	118	(3.1%)
HCFA Submission	127	(3.4%)	9	(8.3%)	136	(3.6%)
NDI	103	(2.8%)	26	(23.9%)	129	(3.4%)
Mail Updates	59	(1.6%)	4	(3.7%)	63	(1.7%)
Criss Cross Directory	55	(1.5%)	39	(35.8%)	94	(2.5%)
Household Enumeration	12	(0)	3	(2.8%)	15	(0)
Social Security	7	(0)	0	-	7	(0)
Vital Statistics Search	3	(0)	3	(2.8%)	6	(0)
Motor Vehicle Relatives	0	(-)	1	(0.9%)	1	(0)
Total Traced	3695	(98.2%)	109	(50.7%)	3804	(95.6%)
Total Not Traced	68	(1.8%)	106	(49.3%)	174	(4.4%)
Total Sample	3763		215		3978	

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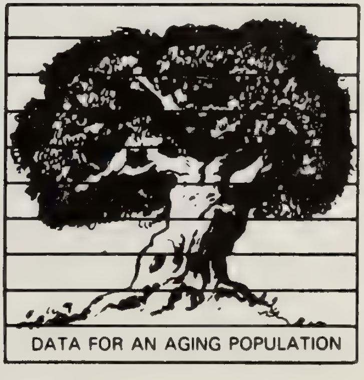
[1] The Best Tracing Source is defined as the first successful tracing source that led to locating the subject.

[2] Original data for the subjects whose vital status was previously confirmed in most cases meant calling the original telephone number. For the lost to followup it meant in-depth review of tracing history in initial followup for missed leads.

Session Q

Impact of Population Migration at the State Level



DATA FOR AN AGING POPULATION

INTERSTATE ELDERLY MIGRATION AND POPULATION REDISTRIBUTION IN THE UNITED STATES

Andrei Rogers, University of Colorado

What is the population geography of the elderly in the United States today? What are the key elderly states, and what do they contribute to total elderly interstate migration? What are the prospects for the future? What are the projected sources of elderly population growth in the key states, and why does it matter? Who are the elderly migrants? These are central questions in any discussion of interstate elderly migration and population redistribution, and they are addressed briefly in this paper.

1. THE POPULATION GEOGRAPHY OF THE ELDERLY IN THE UNITED STATES

Table 1 lists the seven largest general and elderly (aged 65 years and over) state populations in the United States in 1980. California and New York top the two lists, and the same seven states appear in both, albeit in somewhat different order. When the elderly rather than the general population is considered, Florida moves up from seventh to third place and Texas slips from third to fifth place. Together the seven states account for 99,276 million persons, or 44 percent of the total national general population, and 11,594 million persons, or 45 percent of the total national elderly population. The elderly fraction of the total national population is 11.3 percent, and only three of the seven states in Table 1 exhibit fractions that exceed this national average: Florida (17.3%), Pennsylvania (12.9%), and New York (12.3%).

Not surprisingly, the largest elderly state populations send out the largest number of outmigrants: New York, California, and Illinois are the top three origin states, and Florida and California are the top two destination states---with Arizona a distant third (Rogers and Watkins, 1986, and Watkins, 1986). Table 2 sets out the projected consequences, with regard to future elderly population totals. Should current migration patterns continue over a 55-year period:

1.) Florida's elderly population will increase almost three-and-a-half times its size in 1980 and will stand at about 5.8 million persons aged 65 years and over---about 30 percent of Florida's projected total population in 2035.
2.) California's elderly population will grow to almost three times its size in 1980, exceeding Florida's elderly population in 2035 by about 1.2 million. But, unlike the case in Florida, California's elderly population will continue to account for a fraction of the total state population that is lower than the national average of 22.8 percent.
3.) New York and Illinois, the first and third most important origin states for elderly migration are expected to double their elderly populations during the 1980-2035 projection period and to mirror the nation's 22 percent elderly share.

Aggregate projected totals hide important patterns that underlie the expected growth of the elderly population. And these patterns have important implications for policy. We, therefore, turn now to the identification of the sources of the projected growth described in Table 2 and ask what are the contributions of net migration and of "aging-in-place" to that growth.

2. THE SOURCES OF ELDERLY POPULATION GROWTH

Elderly populations can increase only because of an excess of inmigration over outmigration among elderly persons, and/or an excess of persons entering the first elderly age group (65-69 years in our case) over persons exiting the elderly population due to death. The first is called positive elderly net migration, the second is referred to as positive net aging-in-place. The contribution of the former in a constant coefficient projection model is essentially a straight line, that of the latter reflects the influence of changing age compositions, which in turn reflect past fertility and mortality regimes.

Figure 1 sets out two V-shaped patterns. The first (Figure 1A) illustrates the annual rate of growth of the elderly population during the period 1980-2020. The second (Figure 1B) presents the crude birth rate of the total population 65 years earlier, that is, from 1915-1955. Not surprisingly, the former is a mirror image of the latter. One would expect declining mortality (greater longevity) to have played an important role as well, and indeed it did, but its influence is difficult to identify in Figure 1B. However, a closer examination of the right-hand side of both illustrations in Figure 1 reveals that the projected rise of the elderly growth rate occurs faster and reaches a higher level than the corresponding rise of the crude birth rate 65 years earlier. That difference is a direct consequence of the decline in mortality over the 65-year period.

If the V-shaped curve of Figure 1A describes the profile of the annual growth rate of an elderly state population, and if an approximately straight line describes the contribution of elderly net migration, then the combination of the two, also a V-shaped curve, must define the associated contribution of net aging-in-place. Rogers and Woodward (1986) show that this indeed is the case and their model yields the decompositions of sources of growth that are presented in Table 3 (see also, Woodward, 1987).

The two net components of elderly population growth---net aging-in-place and net migration---and their respective contributions to the annual growth rate of the population reveal interesting variations over time, both within and between the four key elderly migration states.

The evolution of the contribution of the net aging-in-place component is broadly similar for all four states. For example, its V-shaped profile produces negative net aging-in-place in three of the four states (and zero growth in California) around the turn of the century, when the "Depression babies" born in the 1930s enter the elderly population. Florida's and California's positive elderly net migration rates more than offset this dip in the profile and give these two elderly populations positive annual growth rates, even during the 1995-2005 period; New York's and Illinois's negative elderly net migration rates, however, when combined with their negative aging-in-place rates, of course give rise to negative annual growth rates.

Table 3 reveals that the principal source of elderly population growth in Florida is net migration, in California that growth is due mostly to net aging-in-place, and in both New York and Illinois it is entirely due to net aging-in-place. The general temporal pattern of the rate of elderly population growth in each of the four key elderly states is a V-shaped curve, of the form exhibited by the national elderly population---appropriately raised or lowered to reflect the approximately linear contribution of each state's elderly net migration rates during the projection period.

Variations among projected state-specific annual elderly population growth rates are significant. For Florida they range from an initial high of 3.8 percent to a low of 0.5 percent, around the turn of the century, and a subsequent high of 2.6 percent at the end of the 40-year projection period. The corresponding rates for New York are an initial high of 0.4 percent, followed by a low of -1.3 percent, and ending with a high of 0.8 percent. The ranges for California and Illinois generally lie inside of these two extreme cases.

Why should anyone be interested in the relative importance of sources of elderly population growth? Of what policy relevance is this? To answer this question, one must address the related matter of the selectivity of elderly migrants: How do they differ from each other and from non-migrants?

3. WHO ARE THE ELDERLY MIGRANTS?

Elderly populations growing mostly from net migration have different demographic and socioeconomic characteristics than do those that grow mostly or entirely from net aging-in-place. This is because elderly non-migrants generally have different attributes than do elderly interstate outmigrants, and because elderly interstate outmigrants often have different attributes than do elderly interstate inmigrants. For example, consider the totally different age patterns of elderly migration illustrated in Figure 2, which contrasts the New York to Florida migration stream with its counterstream. The New York to Florida migration schedule illustrates a dominant "amenity/retirement-related" age profile with its remarkably prominent retirement peak, centered around age 65 for males and at about age 60 for females. The Florida to New York migration schedule, on the other hand, presents the standard "assistance-related" age profile, with its characteristic upswing at the oldest ages, particularly for widows returning "home" after the death of their husband.

The "selectivity" of elderly migrants, on indices other than age, has been identified in a number of studies (for example, Biggar, 1980) leading Charles Longino, Jr., to conclude:

> "Migration is not just a numbers game. Though some states gain migrants and other states lose, more important than the numbers to local business and government planners are who moves in and who moves out. This is especially true for older migrants; while some are healthy, active, and financially well- off, others are sickly, dependent, and poor. In the exchange of older migrants between pairs of states, some states are enriched because well-off, active residents move in. Others tend to lose in the exchange because more of their independent older people go to another state and they gain back those more dependent on social services." (Longino, 1985, p.7)

Longino's conclusion addresses the heart of the public policy issue. State elderly populations that are growing entirely from net aging-in-place, such as New York's, are losing their younger, well-off elderly and are gaining older, more dependent elderly, who are much more dependent on local public services and institutions. On the other hand, state elderly populations that are growing mostly from elderly net migration, such as Florida's, benefit from the expenditures of pension and retirement funds that increase the local demand for goods and services, without adding significant costs to the collective welfare burden. Yet many state-run programs are funded on the basis of elderly population totals and not on the basis of the demographic and socioeconomic profiles of those totals. In this way, states such as New York are "short-changed" in favor of states such as Florida.

4. CONCLUSION

Long-range projections by the U.S. Census Bureau suggest an ultimate stabilization of the U.S. elderly population around the third quarter of the next century (U.S. Bureau of the Census, 1983b). The middle-series projections indicate an ultimate U.S. general population of some 310 million and a corresponding elderly population total of about 70 million persons, or approximately 22 percent of the national total. At this point the V-shaped pattern of Figure 1 will have evolved into a straight line depicting a zero annual growth rate commensurate with a crude birth rate of about 15 per thousand. What will be the elderly state population shares of this ultimate total?

Forecasts of migration are notoriously inaccurate, and past trends of elderly migration may suddenly change. Nevertheless, elderly migration to Florida has shown remarkable stability over three census decades, and a continuation of that state's dominant position in the population geography of the elderly is a likely prospect as long as climate plays a primary role in the retirement migration decision. We expect, therefore, that Florida will still be a prominent location for retirement migration a hundred years from now. And the same may be true of California. But there are signs that other Sunbelt states (for example, Arizona, North Carolina, and Texas) will become strong competitors in the future, and this will alter the level of the line depicting the contribution of elderly net migration as a source of population growth. Consequently, even though zero elderly population growth (ZEPG) is in prospect at the national level, no such prospect is evident at the state level. Thus planners will need to continue to monitor patterns of elderly migration and the selectivity of elderly migrants. And they will need to continue their efforts to improve the quality of forecasts of state elderly populations.

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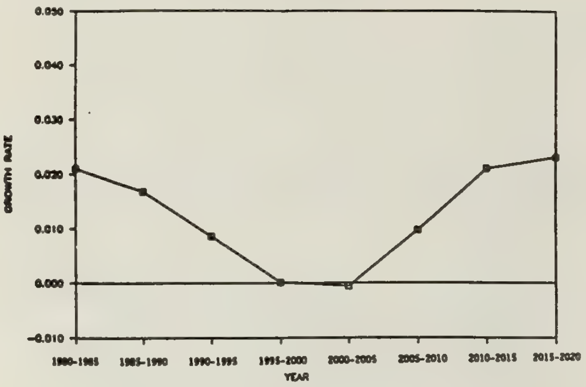
1.A Current and Future Elderly Growth Rates



1.B Past Birth Rates

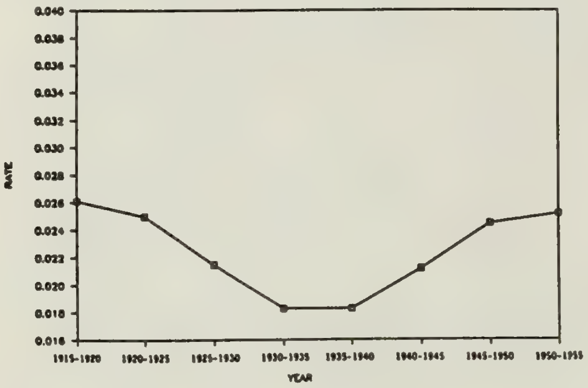
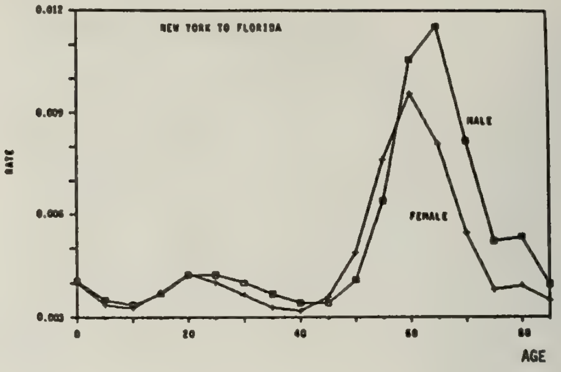


Figure 1. Annual Rates

Sources: Rogers and Woodward (1986) and Easterlin (1980).

2.A New York to Florida



2.B Florida to New York

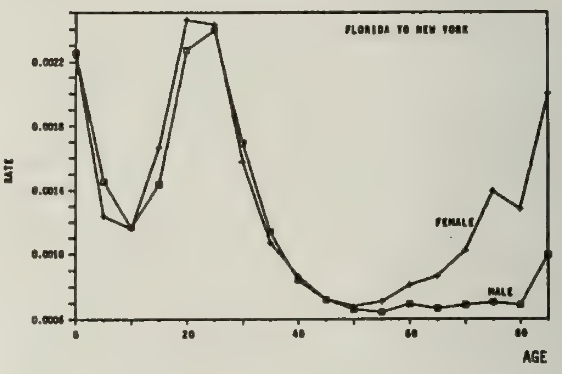


Figure 2. Age Patterns of Elderly Migration

Source: Watkins (1986).

Table 1. The Seven Largest General and Elderly (Age 65 Years and Over) State Populations in 1980

General (Total) Population				Elderly Population			
Rank	State	Population (in thousands)	% (US)	Rank	State	Population (in thousands)	% (65+)
1	California	23,669	10.4	1	California	2,415	10.2
2	New York	17,557	7.8	2	New York	2,161	12.3
3	Texas	14,228	6.3	3	Florida	1,685	17.3
4	Pennsylvania	11,867	5.2	4	Pennsylvania	1,531	12.9
5	Illinois	11,418	5.0	5	Texas	1,371	9.6
6	Ohio	10,797	4.8	6	Illinois	1,261	11.0
7	Florida	9,740	4.3	7	Ohio	1,170	10.8
Total for the United States		226,505	100.0			25,544	11.3

Source: Bureau of the Census (1983a).

Table 2. The Elderly (Age 65 Years and Over) Population, Its Projected Increase, and Its Share of the Total Population: United States and Selected States, 1980-2035

	Elderly Population (in millions)			Increase Multiplier (1980=100)			Elderly Share (Percent Aged)		
	1980	2000	2035	1980	2000	2035	1980	2000	2035
United States	25.5	35.0	66.9	100	137	262	11.3	13.1	21.8
Florida	1.7	3.8	5.8	100	223	345	17.3	21.5	30.5
California	2.4	3.5	7.0	100	146	292	10.2	11.4	19.3
New York	2.2	2.1	4.5	100	95	205	12.3	13.9	22.5
Illinois	1.3	1.4	2.7	100	108	208	11.0	12.3	21.8

Sources: Bureau of the Census (1983a) for the 1980 and 2000 data; Bureau of Economic Analysis (1985) for the 2035 projections.

Table 3. Components of Projected Annual Elderly Growth Rates

Year	Net Aging-in-Place Portion	Net Migration Portion	Annual Growth Rate
3.1 Florida			
1980-1985	0.012437	0.025559	0.037996
1985-1990	0.004557	0.022532	0.027089
1990-1995	-0.001563	0.019869	0.018306
1995-2000	-0.009766	0.017458	0.007692
2000-2005	-0.011072	0.016495	0.005423
2005-2010	-0.005235	0.017173	0.011938
2010-2015	0.004748	0.018641	0.023389
2015-2020	0.006816	0.018747	0.025563
3.2 California			
1980-1985	0.020083	0.003872	0.023955
1985-1990	0.016816	0.003564	0.020379
1990-1995	0.008693	0.003073	0.011766
1995-2000	0.000297	0.002723	0.003021
2000-2005	0.000302	0.002675	0.002977
2005-2010	0.009147	0.002871	0.012018
2010-2015	0.022188	0.003093	0.025281
2015-2020	0.022963	0.002904	0.025867
3.3 New York			
1980-1985	0.010280	-0.006560	0.003720
1985-1990	0.006242	-0.006185	0.000057
1990-1995	0.002233	-0.006157	-0.003924
1995-2000	-0.006968	-0.006076	-0.013044
2000-2005	-0.007318	-0.005633	-0.012951
2005-2010	0.001587	-0.005081	-0.003494
2010-2015	0.012950	-0.004673	0.008277
2015-2020	0.012742	-0.004619	0.008123
3.4 Illinois			
1980-1985	0.014035	-0.003137	0.010898
1985-1990	0.008931	-0.002887	0.006044
1990-1995	0.003848	-0.002886	0.000961
1995-2000	-0.005394	-0.002820	-0.008214
2000-2005	-0.004740	-0.002443	-0.007182
2005-2010	0.003734	-0.001992	0.001714
2010-2015	0.016043	-0.001519	0.014451
2015-2020	0.019418	-0.001548	0.017870

Source: Rogers and Woodward (1986)

THE IMPACT OF RETIREMENT MIGRATION

Charles F. Longino, Jr., University of Miami

One does not have to live in a college town to understand that migration affects the local community. If you live in a resort community, the seasonal flow can also be dramatic. Geraldine Page received an academy award this year for her performance in "Trip to Bountiful," a story about the deaths (due largely to out-migration) of the rural communities that once dotted south Texas. And Antelope, Oregon, experienced the strains of both in- and out-migration during the past decade.

When it comes to the migration of older persons, there are many cultural notions that precede and shape scientific inquiry. There is an impression in some parts of the region in which I grew up, the South, that retirement migration is Grant's revenge. One senses the low grade anxiety in statements decrying the burden placed on local social services by all those poor old people moving down from up North. There is more than a hint of Southern localism in this sentiment and perhaps an undertone of xenophobia as well; after all, if all those old Yankees move down here, there won't be enough help to go around for our own old folks at home. It reminds one of the fear of oriental immigration in California nearly a century ago that came to be called the yellow peril (Longino and Biggar, 1981).

This gray peril mentality, it turns out, has been very hard to document. In the South, outside of Florida, for example, there is not a lot of elderly in-migration, and the little that occurs is so often made up of return migrants to the South (and other southerners just switching states) that the migrants do not stand out at all (Serow, 1978; Longino, 1979, Biggar, 1979, 1984). One would expect that they are often older relatives of local middle-aged Southerners. Older in-migrants do not seem so threatening or needy in the South when they are not "outsiders." I would guess that this is the situation with the impact of older migrants on most states, not just in the South.

Seasonal fluctuations in the older population also provide fertile ground for the gray peril mentality. It is reasonable to inquire about the extent to which elderly seasonal migrants compete with the permanently settled older population for local resources and services. Monahan and Greene (1982) surveyed the older residents in several places in Tucson, Arizona, at the height of the winter visitor season and compared the permanent and seasonal residents. Then they documented peak load fluctuations in many agencies providing services in health care, social service, transportation, housing, and information and referral. When the agency and the individual data were compared, the researchers found that older seasonal migrants tended to be socially independent persons whose use of locally subsidized resources is slight. They concluded that elderly winter visitors do not create demands on local resources that are significantly detrimental to the local older population.

A more recent survey analysis of older Canadians who winter in Florida also found that the use of local state-subsidized resources is negligible among these seasonal migrants. They tend overwhelmingly to buy their services from the private sector and, in this aspect, to have very little impact on the local community. The search for local public service impact on specialized aging services has turned up disappointingly little evidence for the gray peril.

Fear of the older migrating hoard is most often heard in those destinations where retirement migration is a major feature of the demographic landscape, such as Florida, Arizona and California and in other scattered counties that feature water, mountains or both. The controversy took an interesting twist in the past two years, this time on a macro-level. The Retirement Migration Project (funded by the National Institute on Aging) analysed the Sample A 1980 census microdata files and found that in addition to the large and established migration streams between major sending and receiving states, there are often smaller counter-streams going in the opposite direction (Longino, 1979).

In the 1980 census, 20 such exchanges between states were found. See Table 1. The pair of reciprocal streams of older migrants that received the most attention, however, were those between New York and Florida (Longino, 1985).

New York recaptures only 7 percent of the number of migrants it trades with Florida, so there's not much danger of that small counter-stream having a profound impact on the Empire State. Table 2 shows that on a nose count, because of the flood of Florida in-migrants and the relatively small trickle back to New York, Florida gets ~~more older~~ migrants of almost any census characteristic than it sends--more of the very old, widowed and poor ones. For this reason, Florida's health and service planners argue that their state is a loser in its exchanges with New York and other major sending states (Longino, 1984).

Although this may be true, on a nose count, Florida is still a winner in the exchanges. Most Florida in-migrants have very positive characteristics. Only looking at the numbers hides that fact. Table 3 describes the characteristics of the migrants in each of the major state exchanges with Florida in terms of their proportions. It is clear from this table that Florida not only benefits from its in-migrants, but from its out-migrants as well. Florida gains because its older newcomers rejuvenate and enrich Florida's population, whereas among the out-migrants are the people most demanding of Florida's health and social service system: the very old, the poor, the widowed and the dependent (Litwak and Longino, 1987).

In a recent study at Brandeis University (Crown, 1987), for example, the 1975-80 counter-stream data from the Retirement Migration Project was combined with data from the 1980-81 Consumer Expenditure Survey in a first-cut attempt to get a handle on the state economic impact of retirement migration. The total interstate distribution of income among the 828,000 migrating households was 15.2 billion dollars (in 1979 dollars) for households whose householders were over age 60. When household income was adjusted to reflect after-tax income it was $16,545. Because older households spend slightly more than their incomes, these figures are a conservative estimate of consumption changes. There were 70,306 older households in the New York to Florida migration stream, so the consumption gain to Florida was 1.16 billion dollars. Florida lost 57 million dollars from the stream going to New York. The net gain to Florida, therefore, was over a billion dollars.

Certainly a significant part of that billion dollars finds its way into the tax coffers in Florida. But beyond the direct impact of this consumption, a careful study of the indirect economic impact on Florida of older in-migrants might show that the increased consumption of these new residents also increases the industrial production, the employment, and the payrolls in Florida, increasing thereby the tax revenue more than enough to cover the service burden that the more needy of these migrants bring to Florida. If this is so, then Florida is indeed the winner in these exchanges, Table 2 not withstanding (Longino and Crown, 1987).

The "phoenix factor" in what I am calling the gray peril mentality derives primarily from its policy import. Anxiety that older migrants carry with them a hidden and perilous cost to the major receiving states arises from the ashes time and again. To use another image, the Trojan horse of consumption may hide a much higher delayed cost for health care and human services. And since the gates of Troy, or for that matter, of Ft. Lauderdale, Cape May or old Tucson, cannot be locked to older migrants, anxiety about the relative value of their gifts remains a nagging and ever-renewing policy concern.

Nowhere is the direct impact of such migration on government expenditures estimated. Nor are there studies that compare the aggregate or per capita impact of younger and older migrant households on different types of government expenditures so that the relative burden of age can be assessed.

The expenditures of migrant households and those of local and state governments, of course, are only the first round of impacts in a chain of economic effects that reverberate throughout the interstate economy. Because they consume differently, younger and older migrant households will generate different industrial output and employment effects in each state, as mediated by each state's economy and its economic ties with all other states. For example, older migrant households' demand for hospital facilities in Florida stimulates the production of scientific equipment in Massachusetts, steel in Pennsylvania, lumber in Maine, and so on. The industrial output and employment impacts of younger and older migrant households affect each state's economy, not just the major receiving states (Longino and Crown, 1987).

The research agenda on migration impact, it seems to me, must address these broader issues before the gray peril terror can be assessed adequately and then put to rest, perhaps with a stake in its heart, or allowed to live in the daylight, supported by some credible scientific evidence.

Table 1. Major 1975-1980 Interstate Migration Exchanges of Persons Age 60+

Origin State	Destination State	Volume	Return Volume	Returning per 100 in stream
California	Arizona	16,440	8,600	52.3
California	Nevada	11,680	4,240	36.3
California	Oregon	17,080	5,960	34.9
California	Texas	11,240	6,960	61.9
California	Washington	12,360	5,600	45.3
Connecticut	Florida	13,280	1,720	13.0
Illinois	Arizona	11,520	1,360	11.8
Illinois	California	13,960	3,600	25.8
Illinois	Florida	30,680	3,160	10.3
Indiana	Florida	14,320	1,680	11.7
Maryland	Florida	11,480	1,880	16.4
Massachusetts	Florida	19,840	2,640	13.3
Michigan	Florida	28,320	3,480	12.3
New Jersey	Florida	38,440	4,640	12.1
New York	Florida	127,600	9,000	7.1
New York	New Jersey	24,320	7,120	29.3
New York	California	18,360	2,160	11.8
Ohio	Florida	37,720	5,120	13.6
Pennsylvania	Florida	31,600	4,480	14.2
Pennsylvania	New Jersey	11,480	10,200	88.9

100% population estimates derived from the 1-in-40 mig. sample from PUMS-A, 1980.
Center for Social Research in Aging, University of Miami, Coral Gables, FL 33124

Table 2. Comparison of Characteristics of Migrants Age 60+ in Florida Streams From and To New York, New Jersey, Pennsylvania, and Ohio.

Migrant Characteristics:	New York		New Jersey		Pennsylvania		Ohio	
	To FL	From FL	To FL	From FL	To FL	From FL	To FL	From FL
Total Migrants	127600	9000	38440	4640	31600	4480	37720	5120
Demographic								
# Age 75+	19140	3798	6458	1601	5435	2038	5469	1961
# Male	59844	3042	19451	1522	14789	1640	18596	1720
# White	124155	8559	37863	4440	31126	4440	37494	5079
# Black	2297	324	346	121	348	0	113	41
# No English	4594	198	2768	520	263	0	264	41
# Hispanic	6380	558	3075	399	253	40	189	0
# Married	76593	3438	28984	2162	23574	1998	29572	2079
# Widowed	21820	4437	6496	2000	5814	1998	5884	2560
# Return Mig.	893	5040	154	1360	284	2881	339	2038
# w Disability	10208	1836	3344	840	2402	802	2980	1080
Living Arrangements								
# Living Alone	17992	2403	5036	1202	3855	1241	4640	1439
# Live Independ	115223	5643	34135	3081	28124	3042	34137	3441
# Live w Child	5742	1800	2037	798	1675	560	1886	558
# Live w Sibling	2680	198	500	121	348	161	566	282
# In Institution	1148	1080	500	200	632	600	490	681
# In Home/Aged	1021	801	423	162	600	520	377	681
Socioeconomic								
# Some College	33304	1602	8995	362	7837	681	9619	722
# Labor Force	14674	999	5189	520	3002	439	3885	399
# Own Home	97869	3753	30829	2199	25596	1801	31345	2079
# Welfare Inc.	4849	603	1845	399	885	161	1169	323
# 200%+ P. L.	94552	4878	27754	2719	23068	2598	27347	2519
# Below Poverty	8677	1044	2921	719	1201	282	2037	440

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	To FL	From FL	To FL	From FL	To FL	From FL	To FL	From FL
Total Migrants	127600	9000	38440	4640	31600	4480	37720	5120
Demographic								
Mean Age	68.2	73.2	68.2	72.4	68.3	73.3	68.0	73.1
% Age 75+	15.0	42.2	16.8	34.5	17.2	45.5	14.5	38.3
% Male	46.9	33.8	50.6	32.8	46.8	36.6	49.3	33.6
% White	97.3	95.1	98.5	95.7	98.5	99.1	99.4	99.2
% Black	1.8	3.6	0.9	2.6	1.1	0.0	0.3	0.8
% No English	3.6	2.2	7.2	11.2	0.8	0.0	0.7	0.8
% Hispanic	5.0	6.2	8.0	8.6	0.8	0.9	0.5	0.0
% Married	75.7	38.2	75.4	46.6	74.6	44.6	78.4	40.6
% Widowed	17.1	49.3	16.9	43.1	18.4	44.6	15.6	50.0
% Return Mig.	0.7	56.0	0.4	29.3	0.9	64.3	0.9	39.8
% w Disability	8.0	20.4	8.7	18.1	7.6	17.9	7.9	21.1
Living Arrangements								
% Live Alone	14.1	26.7	13.1	25.9	12.2	27.7	12.3	28.1
% Live Independ.	90.3	62.7	88.8	66.4	89.0	67.9	90.5	67.2
% Live w Child	4.5	20.0	5.3	17.2	5.3	12.5	5.0	10.9
% Live w Sibling	2.1	2.2	1.3	2.6	1.1	3.6	1.5	5.5
% In Institution	0.9	12.0	1.3	4.3	2.0	13.4	1.3	13.3
% In Home/Aged	0.8	8.9	1.1	3.5	1.9	11.6	1.0	13.3
Socioeconomic								
Yrs. Schooling	11.4	10.3	11.1	9.5	11.7	10.1	11.7	10.5
% Some College	26.1	17.8	23.4	7.8	24.8	15.2	25.5	14.1
% Labor Force	11.5	11.1	13.5	11.2	9.5	9.8	10.3	7.8
% Own Home	76.7	41.7	80.2	47.4	81.0	40.2	83.1	40.6
% Welfare Inc.	3.8	6.7	4.8	8.6	2.8	3.6	3.1	6.3
Job Inc.	9656	8420	11173	6873	8960	6927	9820	8885
Business Inc.	10866	20755	10171	-	12574	-	6173	-
Investment Inc.	4854	3366	5428	4340	4973	3287	4046	5680
Soc. Sec. Inc.	3645	3448	3644	3021	3424	3528	3590	3159
Welfare Inc.	2489	2140	2036	2651	2655	533	2868	1954
Pension Etc Inc.	5618	3197	5267	3903	6230	5417	5141	3213
Personal Inc.	9952	6888	10404	6578	10051	7029	9286	7422
Household Inc.	18062	18124	18569	17399	18079	16113	16453	16391
% 200%+ P. L.	74.1	54.2	72.2	58.6	73.0	58.0	72.5	49.2
% Below Poverty	6.8	11.6	7.6	15.5	3.8	6.3	5.4	8.6

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CONSEQUENCES OF ELDERLY MIGRATION IN THE UNITED STATES

W.J. Serow and D.F. Sly, Florida State University

INTRODUCTION

The purpose of this paper is to investigate some of the demographic and associated economic consequences of elderly migration within the United States. The data covered here are from the 1980 Census of Population and pertain to the period 1975 to 1980. As is well known, these data permit comparisons of place of residence for those persons who were alive at the beginning of the period and who survived until its end. Because the comparison is limited to two points in time, it is not possible to account for return or multiple moves over the interval. A person can have only one move during the period; this would occur if the 1980 place of residence differs from that of 1975. Migration is defined as occuring when the 1975 and 1980 residences are located in different counties. In addition to providing a comprehensive picture of population redistribution through internal migration, these data also permit consideration of the role played by immigration (but not emigration) in the movement of the older population.[1]

The paper will begin with a discussion of the extent to which older persons, here defined as individuals aged at least 55 in 1980, changed residence during the 1975-80 period. This section concentrates on observed differences by age, gender, and distance moved. From there, the paper explores some of the dimensions by which elderly migration has reshaped the spatial distribution of this population; among the issues considered here are metropolitan/nonmetropolitan residence, as well as region and state of residence. The final section of the paper treats some of the probable consequences of this redistribution.

DIFFERENCES BY AGE, GENDER AND DISTANCE MOVED

Residential mobility is usually considered to be a phenomenon of the young. Model migration schedules show pronounced regularity in age-specific patterns of movement, with a peak at age 20-25 and gradual decline thereafter. There is often a secondary peak around the age of retirement (Rogers and Castro, 1981).

We would contend that much of the previous analysis of mobility among the elderly has been conducted at too great a level of aggregation to consider age patterns and differentials in mobility within the older population. There can be no question that mobility for the United States during the period 1975-80 conformed to the general pattern: mobility rates were at a maximum for persons aged 25-29 in 1980 and declined quite consistently with age. Slightly more than half of all persons aged 5-54 had moved between 1975 and 1980, compared with slightly less than one fourth of those aged 55 and over. Persons aged 65 and over were marginally less likely to move than were persons aged 55 to 64. However, with greater disaggregation, it becomes clear that overall residential mobility actually increases with age. As shown in table 1, the share of the population which had moved declined gradually from 24 to 21 percent from aged 55-59 to 75-79, but then rose to 32 percent among persons aged 90 and over. The pattern was identical for males and females, although females had higher total mobility rates at all ages greater than 60 and the differential, both absolutely and relatively, tended to widen with age.

The reason for both the age and gender patterns probably lies in our increased understanding that mobility of older persons is not a unidimensional phenomenon associated only with retirement to salubrious climes; rather, it is closely tied to life course phenomena, wherein retirement, bereavement and failing health intervene at different stages of the elderly life course to stimulate residential mobility. Hence, one might expect to find retirement migration among young-old couples, but care seeking migration among older widow(er)s, possibly followed by another move into an institution (Litwak and Longino, 1987; Serow, 1987b). Because the probability that an intact marriage will be dissolved by the death of the husband greatly exceeds that by death of the wife, it follows that the need for care and support will occasion more residential mobility among older women than among older men.

These differences are also reflected in the relationship between age and distance moved. As a crude proxy for distance, we employ the concepts of interstate versus intrastate moves, although the crossing of some politically defined boundary is admittedly an imperfect substitute for the actual distance moved. In any event, the proportion of interstate movers among the elderly is at its highest for ages 60-69, precisely the age at which one would anticipate the greatest tendency for retirement migration. Even though the proportion of the population making an interstate move increases after age 85, interstate moves account for almost one fourth of all moves for persons in their sixties, but only about one seventh of all moves among persons more than 85 years of age.

METROPOLITAN/NONMETROPOLITAN RESIDENCE

During the 1970s, the long standing tendency of the American population to become concentrated into metropolitan areas was reversed. Older persons played a not unimportant role in the so-called "nonmetropolitan turnaround" and indeed Fuguitt and Tordella (1980) argue that "..elderly migrants were the harbingers of the nonmetropolitan turnaround" (p.191) in that since at least 1960 persons aged 65 and over had moved, on balance, from metropolitan to nonmetropolitan areas, while the same phenomenon did not emerge within the younger population until after 1970. As shown in table 2, there was a net interchange of persons aged 55 and over favoring nonmetropolitan areas which amounted to more than 200,000 persons. As Litwak and Longino (1987) note, it may be that "..more of the older people moving from metropolitan to nonmetropolitan locations may be making their first post-retirement move." (p.270) While the causes of the turnaround among the elderly need not be repeated here (see, for example, Flynn et al., 1985), the differences in this aspect of redistributive behavior within the older population need to be considered. As table 2 suggests, the net migration of the elderly from metropolitan to nonmetropolitan areas is entirely due to the younger (55-74) element of this population. Among persons aged 75 and over, the net flow is reversed.

Within metropolitan areas, it is often useful to divide the population into residents of the central city and suburban (ring) portions. The social, demographic and economic structure of the two areal types is quite different on the whole. For all older persons, all population losses through migration to nonmetropolitan areas were from suburban areas; there was a positive, though small, net inflow into central cities. Once again these phenomena reflect the behavior of the younger elderly. For those aged 55-74, net losses from the suburbs were about 280,000 while net gains to central cities were some 50,000. At ages 75 and above, however, the directional balance of these flows was reversed, with net movement of 22,000 to suburbs and net movement from central cities of 3,000. While all of these figures are rather small and, being derived from a sample, possibly statistically insignificant, there seems to be sufficient consistency in flow direction, especially after age 80, to conclude that this aspect of redistribution differs between the younger and older segments of the elderly.

Clearly, the critical question here is why do these differences exist. We would suggest that they might reflect the other side of the retirement migration coin. Because this is an economically selective process (Biggar, 1980), it is likely that a relatively large share of such migrants originated in comparatively affluent areas such as suburbs. Among the older elderly, for whom care seeking moves are important. the logical direction of the move would be toward the home of a caregiver (most probably an adult child or other relative) and/or to an institution. The adult children are also relatively likely to live in suburban areas, for the same reasons as we would expect their returning parents to have originated there. Thus, the movement to suburbs among those aged 75 and over is also quite consistent with the multi-stage late life mobility hypothesis.

REDISTRIBUTION OF THE ELDERLY AT THE REGIONAL AND STATE LEVELS

Table 3 presents data which illustrate the effects of population movement among persons aged 55 and over (in 1980) on the regional distribution of this population. In the case of internal migration, it is clear that older persons moved, on balance, from the Northeast and Midwest regions to the South and West. Overall, the Northeast lost some 405,000 older persons due to migration, or 3.5 percent of the region's enumerated 1980 population. The Midwest lost some 312,000 persons (2.5 percent); corresponding gains in the South and West were 562,000 and 155,000 (respectively), or increases of 3.6 and 1.9 percent. These overall patterns persist over all ages, although the relative size of in- and decrements diminishes somewhat with age; at ages 75 and above decrements to the Northeast and Midwest decline to 2.1 and 1.1 percent, while increments to the South and West decline to 1.6 and 1.7 percent, respectively.

During the period 1975 to 1980, the population aged 55 and over was increased by movement from abroad; the number of persons in this age group living in the United States in 1980 but elsewhere in 1975 was about 250,000.[2] Although this volume is too small to have any measurable impact on the regional distribution of the older population (accounting as it does for about 0.5 percent of the nation's elderly population in 1980), the regional distribution of movers from abroad does differ markedly from the locational pattern of the non-immigrant elderly. Most notably, more than one third of older immigrants were to be found in the West, a share about twice that region's share of indigenous elderly. On the other hand, only a tenth of immigrants, but a fourth of other elderly were in the Midwest region. For the other two regions, immigrants were marginally overrepresented in the Northeast and marginally underrepresented in the South. These general relationships held across all older age groups.

The redistributive trends at the regional level become magnified when the data are further disaggregated to the state level. Table 4 summarizes these data for selected states [more detailed tables are available upon request]. Elsewhere (Serow, 1987a), we have noted the concentration of high rates of elderly inmigration (in excess of 10 percent of the 1980 population) in a few states: Arizona, Florida, New Mexico and Nevada. Due to the relatively small size of the older population and relatively high rates of elderly outmigration in all these states save Florida, the redistribution of the older population due to internal migration is largely focused on Florida. During the 1975-80 period, there about 2.2 million changes of state of residence among persons aged 55 or more by 1980. The net gain to Florida of persons in this age group was almost 425,000. Florida's nearly 20 percent share of internal migration far exceeded its share of the older population (about 6 percent). Only Arizona and Texas added as many as 50,000 persons aged 55+ to their 1980 population through internal migration.

On the other side of the stream, it is hardly surprising that New York was the state with the greatest relative and absolute losses due to elderly migration. In addition to New York's net loss of more than 250,000 older residents, the states of Illinois, Michigan, Ohio and Pennsylvania each lost more than 50,000 older residents.

As noted above, immigration added about one quarter of a million older persons during the 1975-80 quinquennium. At the regional level, it was clear that these persons were concentrated in the West. At the state level, this pattern becomes even more pronounced - nearly 73,000 (29 percent) were located in California.[3] The only other states with more than 10,000 older immigrants were New York (39,000), Florida (31,000), Texas (14,000), Illinois (12,000), and New Jersey (11,000). All told, more than half of all older immigrants were located in the three primary states of destination.

ECONOMIC CONSEQUENCES OF REDISTRIBUTION OF THE OLDER POPULATION

The economic consequences of population redistribution within the United States are most clearly felt in the principal areas of origin and destination for older migrants. It must be recalled at this juncture that older persons are a diverse and heterogenous group and that from the perspective of economic status, for example, important differences exist along the axes of age, gender, race, marital status, and living arrangements. Other things being equal, older elderly, women, nonwhites, widow(er)s, and persons living alone will have lower income, on average, than other persons (Serow et al., 1987).The interaction of two or more of these status variables would act to compound the extent of adversity in terms of economic well-being. Similarly, health status, particularly the utilization of services and facilities, varies according to these demographic indicators, particularly age and gender (Ray et al., 1987; NCHS, 1984). From this perspective, then, one would want to know the extent of the influence of changes in the older populationthrough migration on receipts and expenditures of state and local governments and upon the demand for various types of health care services and facilities.

Bell et al. (1987) have recently provided estimates of the fiscal impact of the elderly in Florida, which, as noted above, is the one state most influenced by elderly migration. This study, which is not specific to migrants, concluded that persons aged 65 and over paid the same proportion of their income in state and local taxes as do younger persons. Because Florida's tax rates are among the lowest in the nation and are especially favorable for older persons (there is no state income tax or estate duties), it is not certain that such a finding would hold elsewhere. There is, however, no reason to believe that Bell et al would have found different results for migrants and nonmigrants. It is important to remember in the present context that even though the amount of state and local taxes paid after migration to Florida would usually be less than the amount paid in the state of origin prior to migration, the act of migration represents a transfer of revenues from the state of origin to the state of destination.

In addition to considering contributions to tax bases, it is also appropraite to consider the demands for publicly provided goods and services as well as the costs associated with such demands. It might be noted here that per capita social expenditures for older persons in western society typically exceed those for younger persons by a sizeable margin, perhaps as much as 3:1 (van den Boomen, 1981). However, in the context of the US, many of these social expenditures (notably social security and health care) are largely the responsibility of government at the federal, rather than at the state and local levels. Because social security retirement and survivors' benefits, as well as medicare, are fully portable, the migration of older people carries with it the movement of these income streams.

The nature and extent of demands for services among older persons varies widely according to the age and income of the individual. We have noted previously age differences in certain patterns of population mobility within the older population. We noted, for example, the net movement of the younger elderly from metropolitan to nonmetropolitan areas and the net movement in the opposite direction among the older elderly. Litwak and Longino (1987) note that, within the nonmetro to metro stream, disproportionate shares of movers are older (75+), widowed, disabled, living with a child and living in institutions. They also note that the same disproportions are present in what might be termed "reverse" migration streams, such as those with New York as the destination.

The implications of these differences are quite important. The data suggest, but do not conclusively establish, that the principal states of destination receive younger, comparatively affluent migrants, most often married couples. These persons add to the local tax base and probably demand no more in the way of state and locally provided services than would younger inmigrants.[4] It is after the dissolution of the marriage through death of one of the partners that economic problems are more likely to arise and that care and support needs become relatively more important. If, for whatever reason, such an outcome triggers migration, then the public costs of such care and support seeking activity become shifted to the new state of destination. To a disproportionate extent, this destination is the state of birth (Serow, 1978; Longino, 1979).

Existing data simply do not lend themselves to exploring this aspect of elderly migration behavior. To undertake analysis of these questions requires a set of longitudinal data which permits consideration of the effects of life course changes upon the behavior of older persons. At this point, we can only offer the speculation that the economic consequences of elderly migration differ considerably. The leading states of destination may be viewed as "winning" in at least two respects: they benefit from the presence of younger elderly migrants who move at or shortly after the time of retirement and they are spared the demand for some care and support services by the departure of the older elderly to areas where family and friends might be found.

NOTES

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1. For a general discussion of the problems and possibilities associated with this type of data, see Hugo (forthcoming).

2. Presumably there was some movement of older persons in the opposite direction, but reliable data are not available. Warren and Peck (1980) estimated that between 1960 and 1970 there were some 208,000 foreign born emigrants from the US, who were at least age 55 in 1970.

3. In fact, it is only due to this immigration that California was a net recipient of older migrants. Net internal elderly migration was -473 while gross immigration was 72,549. In no other instance was positive net migration to a state entirely the consequence of immigration.

4. Indeed, because they would rarely have school-age children, they probably make less of a demand for locally provided services.

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Table 1. Proportion of the Population Moving, by Age and Gender: United States, 1975-1980

Age in	Total		Male		Female	
1980	Interstate	Intrastate	Interstate	Intrastate	Interstate	Intrastate
55-59	4.7%	19.0%	4.6%	19.2%	4.7%	18.7%
60-64	5.1	17.8	5.1	17.4	5.1	18.1
65-69	5.3	17.4	5.7	16.9	4.9	17.8
70-74	4.2	16.8	4.3	15.7	4.1	17.6
75-79	3.8	17.5	3.7	16.4	3.9	18.2
80-84	3.9	20.2	3.5	17.9	4.1	21.4
85-89	4.4	24.0	3.8	21.3	4.7	25.2
90+	4.6	27.6	4.0	24.3	4.9	29.0
55+	4.7	18.3	4.7	17.6	4.6	18.8
65+	4.5	18.3	4.6	16.9	4.4	19.2
75+	4.0	20.0	3.6	17.9	4.1	21.1
85+	4.4	25.1	3.8	22.2	4.7	26.4

Table 2. Consequences of Elderly Migration for Metropolitan/Nonmetropolitan Residence: United States, 1975-1980

(thousands of persons)

Age in	Central City		Suburbs		Nonmetropolitan	
1980	Population	Net Migration	Population	Net Migration	Population	Net Migration
55-59	3443.5	40.6	5290.8	-110.6	2880.9	70.0
60-64	3002.1	11.7	4373.3	- 97.5	2712.2	85.8
65-69	2662.7	-15.5	3597.0	- 47.6	2522.8	63.1
70-74	2113.1	13.3	2692.3	- 23.8	1992.7	10.6
75-79	1549.5	1.6	1847.5	3.7	1396.7	- 5.3
80-84	963.1	- 0.6	1124.8	9.0	847.2	- 8.4
85+	726.8	- 4.0	847.8	9.7	665.4	- 5.7
55+	14460.8	47.1	19773.5	-257.1	13017.9	210.1
75+	3239.4	- 3.0	3820.1	22.4	2909.3	- 19.4

Table 3. Consequences of Elderly Migration for the Distribution of Population by Region of Residence: United States, 1975-1980

(thousands of persons)

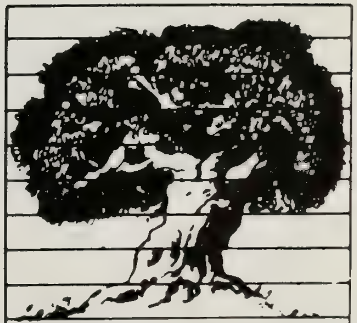
Age in 1980	Population	Internal Migration		From Abroad	Percent of National Total		
					Actual	Without Migration	
		In	Out			Internal	Total
Northeast:							
55-59	2817231	23733	110480	20964	24.0%	24.8%	24.8%
60-64	2473398	17315	121958	15621	24.2	25.2	25.2
65-69	2090877	15532	121158	13016	23.6	24.7	24.7
70-74	1614154	11596	69614	8370	23.4	24.2	24.2
75+	2414654	23569	73204	9943	24.1	24.6	24.6
55+	11410314	91745	496414	67914	23.9	24.7	24.7
Midwest:							
55-59	3015213	41308	114321	8331	25.7%	26.3%	26.5%
60-64	2625156	31271	119804	6314	25.7	26.5	26.6
65-69	2244912	27300	108567	5060	25.3	26.2	26.3
70-74	1771637	22239	60887	3080	25.7	26.2	26.3
75+	2754443	40933	71460	3558	27.5	27.8	27.9
55+	12411361	163051	475039	26343	26.0	26.6	26.7
South:							
55-59	3753390	178772	53148	23422	32.0%	31.0%	31.0%
60-64	3327513	196970	40971	16241	32.5	31.0	31.0
65-69	3014399	188264	35949	11630	34.0	32.2	32.3
70-74	2360625	104672	28451	7438	34.2	33.1	33.1
75+	3190770	104605	52899	7349	31.8	31.3	31.4
55+	15646697	773283	211418	66080	32.8	31.6	31.6
West:							
55-59	2134469	79257	45121	30428	18.2%	17.9%	17.8%
60-64	1808024	74061	36884	22935	17.7	17.3	17.2
65-69	1526042	66336	31758	18191	17.2	16.8	16.7
70-74	1159008	40895	20450	11066	16.8	16.5	16.4
75+	1658389	56650	28194	10689	16.6	16.3	16.2
55+	8285932	317199	162407	93309	17.4	17.0	16.9

Table 4. Net Migration of Persons Aged 55-64 and 65+ by State: United States, 1975-1980

State	Persons 55-64			Persons 65+		
	Population	Net Migration		Population	Net Migration	
		Total	Domestic		Total	Domestic
Alabama	363823	5780	5248	443424	4837	4560
Alaska	21165	-3421	-3650	11176	-2043	-2107
Arizona	261652	44372	42744	309902	41424	40110
Arkansas	225858	15215	14783	314591	8992	8773
California	2232714	26616	-13687	2444704	45460	13214
Colorado	233587	3610	2077	250437	3209	2400
Connecticut	340628	-9551	-11754	365415	-5284	-6936
Delaware	59627	437	139	61209	1445	1322
District of Columbia	64106	-3702	-4623	74905	-5858	-6145
Florida	1135217	224149	207425	1699506	230789	216295
Georgia	467329	7027	5944	521736	8480	7970
Hawaii	85876	3492	573	76029	3170	1214
Idaho	80946	2314	2052	96026	1343	1249
Illinois	1119099	-49127	-55426	1282934	-48824	-54102
Indiana	516913	-12275	-12831	589581	-8067	-8456
Iowa	280618	-5959	-6190	390334	-7001	-7190
Kansas	228534	-1961	-2473	306694	-1634	-1928
Kentucky	335045	2689	2321	413617	-598	-752
Louisiana	355616	1653	377	413714	-355	-994
Maine	107612	2086	1987	142478	321	74
Maryland	408537	-11894	-14462	397479	-3938	-5524
Massachusetts	600437	-13763	-17020	732715	-12291	-15696
Michigan	866122	-31729	-34112	921447	-27860	-29657
Minnesota	361661	-5331	-6241	483998	-5019	-5642
Mississippi	220231	3856	3550	293605	2687	2511
Missouri	485885	1034	96	661368	-2061	-2744
Montana	72241	87	-25	85362	-1001	-1057
Nebraska	145122	-1834	-2068	207249	-1534	-1654
Nevada	77872	11943	11043	65065	7561	7130
New Hampshire	85683	4193	3887	103950	1676	1480
New Jersey	813332	-19883	-26123	861091	-18252	-22648
New Mexico	108431	5133	4526	115135	4048	3807
New York	1835778	-95442	-116027	2181630	-123175	-141654
North Carolina	558965	14588	13632	609472	13341	12951
North Dakota	56780	-1431	-1459	80370	-1463	-1475
Ohio	1076938	-35890	-37815	1180055	-28538	-30145
Oklahoma	282275	6817	6207	378165	2953	2634
Oregon	248679	12487	11395	307940	8082	7391
Pennsylvania	1356995	-21960	-24944	1547051	-23922	-26303
Rhode Island	106253	-545	-1287	127649	-1394	-1889
South Carolina	282062	9183	8500	292435	6991	6658
South Dakota	64529	-674	-749	90967	-1388	-1457
Tennessee	437062	9949	9445	525919	6090	5735
Texas	1189261	35006	26048	1374343	28898	24100
Utah	100902	2196	1796	108883	2530	2231
Vermont	43911	60	-109	57706	371	293
Virginia	497524	800	-2532	511575	5069	3385
Washington	382762	15854	12585	434738	10975	9257
West Virginia	198365	-267	-379	240099	-3164	-3237
Wisconsin	438168	-1724	-2278	575995	-5355	-5992
Wyoming	35666	-7	-116	38042	-1333	-1360
UNITED STATES	21954394	144256	0	25799910	109390	0

Session R

Public Policy and International Data



DATA FOR AN AGING POPULATION

AN AGING WORLD

Barbara Boyle Torrey, Kevin G. Kinsella, and Cynthia M. Taeuber, U.S. Bureau of the Census

The numerical growth of older people around the world is an extraordinary testimony to the improvement of our lives. Increasing numbers of the elderly are associated with relatively high birth rates 60 or more years ago, reductions in infectious and parasitic diseases, reductions in infant and maternal mortality, and improved nutrition. The elderly are also increasing because of worldwide improvements in public and private health services, education, and income.

The growth of older populations poses a considerable challenge to public policy because our needs change as we age. Rapidly expanding numbers of older people represent a social phenomenon without historical precedent, and one that is bound to alter previously-held stereotypes of older persons. There is a growing awareness that the term "the elderly," as a concept, is an inadequate generalization that obscures the heterogeneous nature of a population group that spans more than 40 years of life. The elderly are at least as diverse as younger age groups in terms of personal and social resources, health, living arrangements, and integration into social life. The disaggregation of statistics on the elderly into narrower age groups reveals important demographic and socioeconomic differences which have direct bearing on policymaking, both present and future.

This report is excerpted from a larger report which will be released by the U.S. Bureau of the Census in 1987. The purpose of this study is to summarize detailed demographic and socioeconomic statistics that have been collected on older populations in 31 countries and to show the enormous potential of this information. In some parts of the report, global data assembled by the United Nations are employed to provide perspective for the discussions of the 31 countries or subsets thereof. The data as a whole now constitute an International Data Base on Aging (IDBA), maintained and updated by the Center for International Research, U.S. Bureau of the Census, in Washington, D.C., and archived at the Inter-university Consortium for Political and Social Research in Ann Arbor, Michigan. To portray the heterogeneity of the elderly, IDBA data have been disaggregated as much as possible into 5-year age groups. Further information regarding IDBA contents and use may be obtained by contacting the Chief, Systems Analysis and Programming Staff, Center for International Research (301-763-4811).

Any chronological demarcation of age boundaries is arbitrary and open to dispute on grounds that it poorly represents biological, physiological, or even psychological dimensions of the human experience, especially as they may differ between societies.[1] Attainment of age 75 may be as extraordinary in one nation as it is commonplace in another. Nevertheless, the establishment of such boundaries is necessary for a descriptive comparison of international aging. In this report, the "older" population refers to people 55 years and over, "elderly" refers to 65 years and over, and the "oldest old" are those who are 80 years and over.

INTERNATIONAL DEMOGRAPHIC TRENDS

The world's elderly population currently is growing at a rate of 2.4 percent per year, much faster than the global population as a whole. This growth rate will result in more than 410 million elderly worldwide by the year 2000 (41 percent in developed countries and 59 percent in developing countries), compared with 290 million today (46 percent in developed countries and 54 percent in developing countries).[2] The number of elderly is expected to continue growing rapidly far into the 21st century.

In developed countries as a whole, the elderly growth rate was 2.4 percent per year from 1950 to 1980. The rate plunged sharply in the early 1980's, a result of the low birth rates that prevailed in many developed countries during and after World War I. Just as quickly, this growth rate now is ascending toward its pre-1980 level. After the turn of the century, elderly growth will again dip briefly as a consequence of lowered fertility during World War II (figure 1).

In developing countries, elderly growth increased rapidly in the 1960's and 1970's, followed by a slackening period which should continue into the early part of the next century. After 2010, numbers of elderly will multiply quickly as the annual growth rate for persons 65 years and over approaches 4 percent.

Twenty-three countries had elderly populations of 2 million or more in 1985 (table A). This total is projected to rise to 50 countries by 2025 (table B). The People's Republic of China will have more than 80 million elderly before the year 2000, and India will reach this mark around 2015. In fact, the elderly populations of many Asian nations will more than double in size over the next four decades (figure 2).

Sweden, with 17 percent of its population 65 years and over in 1985, had the highest proportion elderly among the major countries of the world. It also had the highest proportion 80 years and over (3.5 percent). By 2025, however, when Sweden's proportion elderly is over 22 percent, Denmark and the Federal Republic of Germany also will have reached such a high level, and the rest of Europe and the United States (19.5 percent) will be only a few percentage points behind.

Figure 1

Average Annual Percent Growth of World Population in Developed and Developing Countries

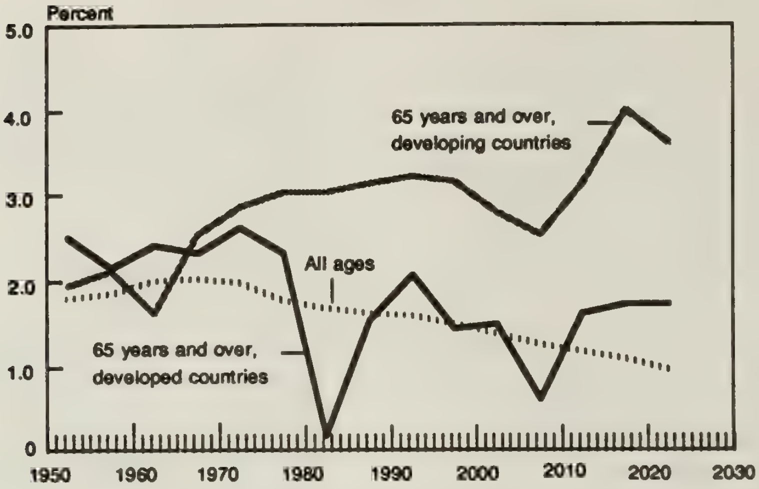


Table A. Countries With More Than 2 Million Elderly in 1985

(Numbers in thousands)

Country	Population aged 65 and over	Country	Population aged 65 and over
China	52,889	Poland	3,484
India	32,698	Bangladesh	3,119
United States	28,609	Pakistan	2,818
Soviet Union	25,974	Mexico	2,797
Japan	12,125	Canada	2,651
Germany (Fed. Rep.)	8,812	Argentina	2,610
United Kingdom	8,466	Vietnam	2,393
Italy	7,443	Nigeria	2,307
France	6,748	Germany (Dem. Rep.)	2,217
Indonesia	5,901	Romania	2,155
Brazil	5,828	Turkey	2,093
Spain	4,274		

Source: United Nations, 1986, unpublished data from the 1984 Assessment of World Population Prospects; and U.S. Bureau of the Census, Center for International Research.

Table B. Countries Projected to Have More Than 2 Million Elderly in 2025

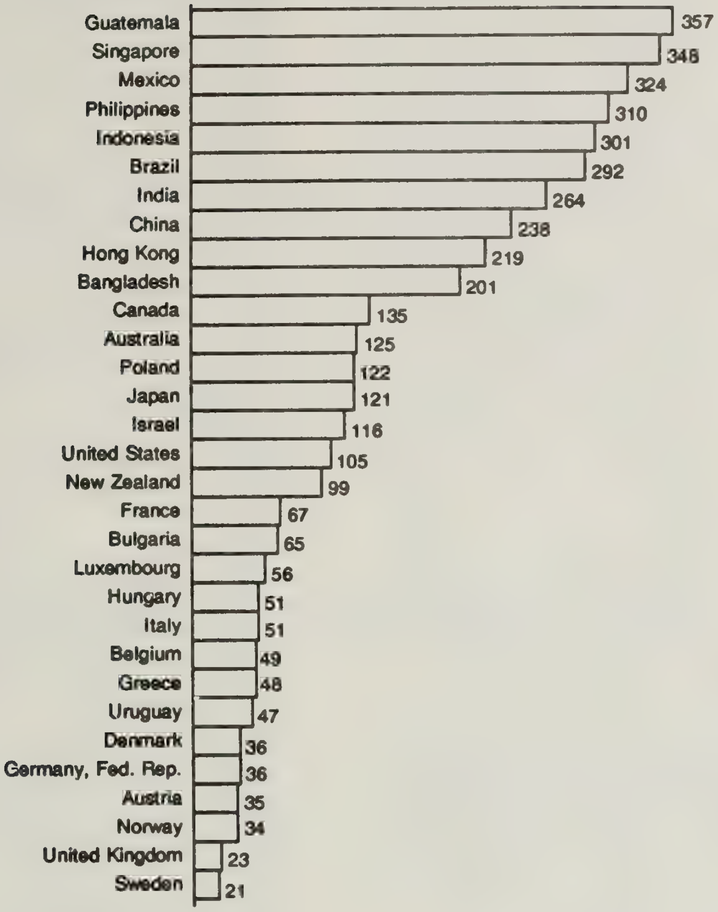
(Numbers in thousands)

Country	Population aged 65 and over	Country	Population aged 65 and over
China	178,150	Burma	5,354
India	118,968	Argentina	5,227
United States	58,771	Yugoslavia	4,638
Soviet Union	54,641	Colombia	4,256
Japan	26,842	Romania	4,252
Indonesia	23,663	South Africa	4,221
Brazil	22,844	Ethiopia	4,104
Germany (Fed. Rep.)	12,017	Australia	3,585
Mexico	11,849	Zaire	3,466
France	11,273	Korea (Dem. People's Rep.)	3,272
Italy	11,221	Netherlands	3,258
Pakistan	10,614	Germany (Dem. Rep.)	3,158
United Kingdom	10,437	Morocco	3,155
Nigeria	9,865	Peru	3,100
Bangladesh	9,386	Czechoslovakia	2,945
Thailand	7,799	Venezuela	2,927
Poland	7,736	Algeria	2,904
Vietnam	7,725	Sri Lanka	2,875
Turkey	7,724	Malaysia	2,529
Philippines	7,687	Sudan	2,498
Korea (Rep.)	7,230	Tanzania	2,437
Spain	7,217	Chile	2,193
Egypt	7,050	Kenya	2,188
Iran	6,422	Iraq	2,166
Canada	6,240	Hungary	2,017

Source: United Nations, 1986, unpublished data from the 1984 Assessment of World Population Prospects; and U.S. Bureau of the Census, Center for International Research.

Figure 2

Percent Increase in Elderly Population: 1985 to 2025



Japan will "age" rapidly during the next 20 years compared with other developed nations. From 1985 through 2005, the 65 to 74 year old population of Japan is expected to experience an average annual growth rate of 2.7 percent, and the population 75 years and over, 2.9 percent. Such growth rates are exceeded only by those in developing countries, where the size of the elderly population is relatively small to begin with and the percentage increases are correspondingly large.

The speed of Japan's aging is almost breathtaking. It will take only 26 years for Japan to double its proportion of elderly from 7 percent to 14 percent (1970 to 1996), compared with 115 years for France and 66 years for the United States (table C). Along with dramatic annual growth rates, the proportion of Japan's population that is elderly will change from moderate to high in comparison with other nations. Today, the elderly are 10 percent of Japan's total population; by 2005, they will reach 16.5 percent, one of the world's highest levels (the Federal Republic of Germany will be 19 percent and Sweden will be 17 percent). And, as in the United States, one consequence of Japan's post-World War II baby boom will be continued expansion of the proportion elderly throughout the first quarter of the 21st century (20 percent by 2025).

Table C. Speed of Population Aging in Selected Countries

Country	Year in which percent of population 65 years and over reached or will reach: 7 percent	14 percent	Number of years required
Japan	1970	1996	26
United Kingdom	1930	1975	45
United States	1944	2010	66
Sweden	1890	1975	85
France	1865	1980	115

Source: U.S. Bureau of the Census, 1984, *Projections of the Population of the United States by Age, Sex, and Race: 1983 to 2080*, Current Population Reports, Series P-25, No. 952, Washington, D.C., table 6; and Japan Ministry of Health and Welfare, 1983, *Annual Report on Health and Welfare for 1983: The Trend of a New Era and Social Security*, Tokyo, p. 141.

In the United States, the proportion of persons 65 years and over will have changed very little by 2005--from today's 12 percent to only 13 percent--even though the absolute number of elderly will rise from 29 million to 36 million during this period. As the post-World War II baby boom matures, however, the proportion of elderly will begin to expand noticeably; from 13 percent in 2005 to nearly 20 percent in 2025, at which time the elderly could number 59 million.[3]

Throughout much of Europe also, the proportion 65 years and over will increase only modestly during the next 20 years. Relatively large gains will be seen in the Soviet Union (9 percent to 13 percent), the Federal Republic of Germany (14 percent to 19 percent), and Southern Europe, while the Scandinavian countries and the United Kingdom, already among the world's "oldest," will see little change in their proportions elderly.

Although three-quarters of the world's population resides in developing areas, such areas presently contain only 54 percent of the world's elderly. Actual proportions of the population 65 years and over change fairly slowly over time in many developing countries because there are so many children and young adults. At the same time, however, the growth rate of the absolute number of elderly is and will be much higher than in developed countries, averaging 3 to 4 percent annually in numerous countries from 1985 through 2025. Because the bases are small, projected increases in excess of 90 percent are not uncommon in developing countries for each of the two successive 20-year periods. By the year 2025, today's developing regions will be home to 69 percent of the world's elderly.

In the People's Republic of China, the world's most populous nation, the political desire to lower fertility rates quickly in the 1970's and early 1980's led to an official policy of one child per married couple. Recent population projections have indicated that an effective nationwide implementation of this policy would result in 40 percent of the total population being 65 years or older by the middle of the next century. In the face of such a prospect, Chinese planners may reconsider their population goals.

In many countries, the elderly population itself is growing older, because of the higher growth rates of the aged (75 years and over) and oldest old relative to persons 65 to 74 years of age. Within the older population, different age groups may have widely different future growth rates due in large part to patterns of fertility 65 or more years ago. While most developed countries will experience growth in the number of persons aged 65 to 74, Sweden and the United Kingdom will register a net loss of persons in this age category between now and 2005, followed by rapid increases after 2005. At the same time, both countries will experience decreases in the average annual change in their younger populations. The pattern of decreased growth in the young population is likewise true for the United States and Japan, and this process is also occurring, though more slowly, in developing countries such as India.

The population 65 to 74 years of age in the United States will grow by only 5 percent during the next 20 years, compared with an explosive 87 percent from 2005 to 2025. In the United States, nearly 9 percent of the population will be 75 years and over in 2025, compared with 5 percent today. In Japan, Denmark, and Sweden, more than 1 out of every 10 citizens will be 75 years or older by 2025.

Persons 80 years and over constitute more than 14 percent of the world's elderly today (19 percent in developed countries and 11 percent in developing nations). In many countries, this age group is projected to be the fastest-growing portion of the elderly population through the middle of the next century.

The oldest old in the United States now number more than 6 million (22 percent of all elderly), and will likely expand to more than 14 million 40 years hence. Shortly after the turn of the century, the United States will have the oldest elderly population of the 31 countries specifically examined in this report--31 percent of elderly Americans will be 80 years old or over in 2005. By 2025, the U.S. will continue to rank highest in this regard (along with Japan), although the proportion of elderly aged 80 and over is projected to decline to less than 25 percent.

Among the 31 study countries, the current percentage of the oldest old in the total population varies from less than 1 percent in most developing countries to 3.5 percent in Sweden. In developing countries, Uruguay and Israel now have the highest proportions 80 years and over; Uruguay's 1.9 percent is actually higher than that of several developed countries, including Japan, Australia, and Poland. By 2025, however, the proportion 80 years and over in developed countries will generally range from 4 to 5 percent, and will exceed Uruguay's 2.7 percent, the highest among developing countries.

The United Nations estimates that China, India, and seven developed countries had over 1 million octogenarians in 1985 (table D). By 2025, this list is expected to include nine additional nations, six of which are developing countries (table E). In some developing countries, the number of the oldest old in 2025 will have increased tenfold since 1975, highlighting the problems governments may have in planning support services for this burgeoning population group.

Table D. Countries With More Than 1 Million Octogenarians in 1985

(Numbers in thousands)

Country	Population aged 80 and over	Country	Population aged 80 and over
United States	6,198	Germany (Fed. Rep.)	1,951
China	5,697	France	1,741
Soviet Union	4,610	United Kingdom	1,732
India	2,913	Italy	1,436
Japan	2,000		

Source: United Nations, 1986, unpublished data from the 1984 Assessment of World Population Prospects; and U.S. Bureau of the Census, Center for International Research.

Table E. Countries Projected to Have More Than 1 Million Octogenarians in 2025

(Numbers in thousands)

Country	Population aged 80 and over	Country	Population aged 80 and over
China	25,208	United Kingdom	2,211
India	16,435	France	2,111
United States	14,348	Mexico	1,894
Soviet Union	9,966	Spain	1,491
Japan	6,531	Poland	1,243
Brazil	3,672	Canada	1,235
Indonesia	3,324	Nigeria	1,135
Germany (Fed. Rep.)	2,855	Turkey	1,043
Italy	2,485	Argentina	1,002

Source: United Nations, 1986, unpublished data from the 1984 Assessment of World Population Prospects; and U.S. Bureau of the Census, Center for International Research.

LIFE EXPECTANCY

Japan's life expectancy of 77 years is the highest among the world's major countries, and life expectancy at birth currently approaches 75 years in most other developed countries. The level of life expectancy is, however, diverse both within and among world regions. At the extreme, developed nations stand in stark contrast to certain developing countries (e.g., Bangladesh and some African nations south of the Sahara) where life expectancy at birth has yet to reach 50 years. Nevertheless, expanded health programs have made an enormous difference in developing countries since World War II. Since 1950, the gain in life expectancy in developing regions has been at least as great as the gain during the entire previous half century. The gap in average life expectancy between developed and developing countries had been reduced to about 17 years by 1980.

In every developed society, women on average live longer than men. The female advantage exceeds 7 years in North America and several European countries, while most other developed nations have female/male differences of 5 to 7 years. Gains over time in life expectancy at birth vary by gender, and mortality differentials between the sexes, particularly at the older ages, have been widening in developed countries for several decades. While current data suggest the possibility of a leveling off or reversal of this trend, it is too early to tell if the difference between male and female life expectancy will in fact narrow.

Differences in life expectancy by sex are usually smaller in developing than in developed nations. The typical worldwide pattern is even reversed in a few developing societies of South Asia and the Middle East, where the interplay of various cultural factors (including low female social status and preference for male versus female offspring) contributes to higher male than female life expectancy at birth.

In the United States and other developed nations, increases in life expectancy at age 65 are now outpacing increases in life expectancy at birth, due largely to the reduction of heart disease and stroke among middle-aged and older adults. While expectation of life at birth in the United States increased by 6 percent from 1960 to 1980, life expectancy at age 65 increased 15 percent during the same period. Similar figures for Japan were 12 percent and 26 percent, respectively.

Japanese women who turned age 65 in 1983 could expect, on average, more than 18 years of additional life; and men, more than 15 years. For both sexes, these figures represent a steady gain of roughly 4 years since 1960.

Although most countries show improving trends in life expectancy akin to those in Japan, some nations have experienced declines in life expectancy at older ages. In Australia, male life expectancy at age 65 fluctuated during the 40-year period from 1930 to 1970, while female life expectancy has shown uninterrupted gains throughout this century. The elderly in Bulgaria (especially men) have lost ground since 1961, even though life expectancy at birth has increased. A similar pattern of decline or stagnation has been reported for other Eastern European nations, and there are indications that this phenomenon may have occurred in India between 1950 and 1980.

SOCIAL CHARACTERISTICS

Numerical population dynamics and changing life expectancies are but two aspects of cross-national comparisons of elderly populations. Equally important are the disaggregation and analysis of additional demographic and socioeconomic data for persons aged 65 and over, which reveal on the one hand similarities shared by virtually all countries of the world, while on the other striking discrepancies among nations and regions. The following excerpts from the forthcoming Census Bureau report highlight some of the more interesting conditions and trends which bear on the status and well-being of older persons worldwide.

Mortality and Health

- In most developed countries, if people do not die in the first 5 years of life, then they are increasingly likely to live to be grandparents.

  Women outlive men in virtually every country of the world.

- The largest difference in mortality rates among countries is because of circulatory diseases.
- Some developing nations may soon be faced with rapidly growing numbers of elderly widows as the differential in male and female life expectancies widens.

Gender Differences

- In developed countries, as much as 70 percent of the oldest old population is female.

Urban and Rural Dimensions

- Seventy percent of the elderly in the world's developed countries live in urban areas, compared with 30 percent in developing countries.

Marital Status and Living Arrangements

- Elderly women are more likely to be widowed than married. The ratio of elderly widows to married women exceeds 2 to 1 in countries such as Austria, Hungary, and the Federal Republic of Germany.
- Throughout the world, elderly persons living alone are increasingly common.

Educational Attainment and Literacy

- The educational attainment of elderly populations is well below that of younger populations, although the discrepancies are narrowing over time.

Social Support of the Elderly

- For most countries, there will be modest increases in the size of the elderly population relative to the size of the working-age population over the next 20 years, but sharp increases from 2005 to 2050.
- The elderly are expected to constitute half of the "dependent" population by 2025, compared with about one-third today.

Labor Force Trends

- Throughout the world, labor force participation of older male workers has declined markedly in the last 25 years. In contrast, rates among older women in developed countries have been rising or holding steady. In developing countries, where retirement systems are not prevalent, older men and women are more likely to remain in the labor force.
- Unemployment rates for older workers have risen during the last decade in almost all Organization for Economic Cooperation and Development (OECD) member countries.

Occupational Characteristics

- Despite a worldwide trend away from employment in agriculture, jobs in this industry remain the primary source of employment for the elderly in most countries.

The Economics of Aging

- In a study of six developed countries, the percentage of elderly with less than half the national median income varies from 1 percent in Sweden to 29 percent in the United Kingdom.

Notes:

[1] George Myers, 1985, "Demographic and Socio-Economic Aspects of Population Aging," Research Project on Population Aging, Initiating Meeting, Committee for International Cooperation in National Research in Demography, Paris.

[2] The "developed" and "developing" country categories used in this report correspond directly to the "more developed" and "less developed" classification employed by the United Nations. Developed countries comprise all nations in Europe (including the Soviet Union) and North America, plus Japan, Australia, and New Zealand. The remaining nations of the world are considered to be developing countries.

[3] The United States produces various series of population projections based on different assumptions. Throughout this report, the U.S. projections refer to the "middle" series. The "lowest" series projects 53.5 million elderly and the "highest" series 65.1 million elderly in 2025.

THE RELEVANCE OF CROSS-NATIONAL DATA AND RESEARCH ON AGING FOR PUBLIC POLICY IN THE UNITED STATES

Nancy Smith, Select Committee on Aging
U.S. House of Representatives

(Not available for publication)

OPPORTUNITIES FOR COLLABORATIVE RESEARCH ON AGING INVOLVING WHO-RELATED PROJECTS

J. E. Dowd, E. Shigan, A. Nissinen, World Health Organization, Geneva, Switzerland

The World Health Organization has had since 1982 a Global Programme on Health of the Elderly whose role is to deal with all health aspects of aging populations, including concerns for the quality of life and the quality of health and social services. The Global Programme has recently laid the ground for an international research programme with the National Institute on Aging whose major thrust will be to establish a rational basis for preventive health care and for elucidating the determinants of healthy aging.

In addition to the many initiatives carried out by the Global Programme on Health for the Elderly at WHO, other programmes carry out studies in specific disease-oriented areas where the major target age groups include the elderly population. This is particularly true of the programmes carried out by the WHO divisions of Noncommunicable Diseases, Mental Health, and Health Situation and Trend Assessment, and is true of the units of Rehabilitation, and Nutrition. This paper will focus primarily on the activities in the Divisions of Noncommunicable Diseases and Health Situation and Trend Assessment to enumerate a series of opportunities for collaborative research capable of addressing policy issues of importance at both national and international level. The programmes of these two divisions are singled out for exposition here, since the division of Noncommunicable Diseases concerns itself with the chronic, degenerative diseases such as cancer, cardiovascular diseases, chronic respiratory diseases, and diabetes, which tend to increase in frequency with age in both developed and developing countries. The Division of Health Situation and Trend Assessment concerns itself with the monitoring and assessment of health status and is thus concerned with classification systems and methodologies for measuring health status and for projecting health trends. A central role of this division is to promote population-based studies of morbidity, disability, and mortality using internationally acceptable indicators, and to establish data bases available to the international community. Before describing in detail projects related to these two WHO programme activities it will be useful to examine some of the main research issues which studies from these areas might address.

It has been noted that the most common causes of mortality in populations aged 65-74 in industrialized countries are the cardiovascular diseases (including stroke) and cancer.(1) Many industrialized countries have shown a decline in cardiovascular disease mortality, including those in the age groups over 60 years of age, with females showing greater percentage declines at all ages. Not all industrial countries show declines in either coronary heart disease or stroke rates at any age and some of the eastern European countries show rapidly increasing rates of ischaemic heart disease mortality below age sixty. Similarly mortality trends in stroke have been decreasing in some industrialized countries while increasing in others.

The situation in developing countries is little known due to lack of cause-specific mortality data by age and sex.

Morbidity data available on cardiovascular disease through special surveys on health in, for example the USA and Japan, do not indicate decreasing trends in cardiovascular morbidity to parallel the decreases in mortality in the older age groups.

With respect to loss of functional capacities and subsequent loss of autonomy, it is known that certain cardiovascular diseases, e.g. congestive heart failure and cerebral stroke, lead to loss of functions and to decrease in autonomy. It is not known, however, to what extent functional loss is due to various cardiovascular diseases, or due to other chronic degenerative diseases of high prevalence in aging populations.

When cardiovascular disease incidence is observed in elderly populations there is still no strong evidence that the risk factors of CVD incidence in the middle-aged will still predict incidence in the elderly. Nor is it known, whether the risk factor levels observed in the elderly still have the same predictive role as they had in the middle-aged. To answer these questions there is a need for:

First, the continuation of mortality follow-up of active long-term cohorts until the entire cohort has died;

Second, the inclusion of repeat risk factor levels examinations and morbidity measurements in the elderly within active cohort studies;

Third, the reactivation of previously examined cohorts of cardiovascular studies of the middle-aged where there has been a diversity of cultural, socioeconomic and health support systems and where the age group of the initially studied population now extends to the elderly range.

It has been noted that classic measurements based on mortality and morbidity are of little use in estimating an individual's functional capacity. Causes of mortality and morbidity tend to be multiple in elderly persons and many morbid conditions go unreported because no health care is sought for them.(2)

Svanborg and his colleagues have also reported that underdiagnosis and overdiagnosis of specific morbid conditions in the elderly are common;(3) underdiagnosis often due to under-reporting of symptoms by the elderly patient, and overdiagnosis often due to the physician misinterpreting symptoms normal in an elderly population, but abnormal in a younger population, as evidence of disease. There is thus seldom a strong correlation between a diagnosis of disease and the functional limitations and consequent loss in autonomy that may be suffered by a particular elderly individual.

A clinical diagnosis of CVD in the elderly may or may not be accompanied by a loss of autonomy. Autonomy or its loss (dependency) depend on a chain of interrelated events which form a conceptual basis for the WHO International Classification of Impairments, Disabilities and Handicaps (WHO-ICIDH). This chain may be summarized as follows:

disease → impairment → disability → handicap.

The impairments represent the signs and symptoms of CVD which can lead to disabilities (loss of specific functional capabilities) which lead to handicaps (loss of autonomy).

These observations have not been studied in any systematic cross-national fashion which would relate the outcomes of loss of autonomy either to risk factors for CVD, or other chronic diseases, or to the age of onset, the severity and duration of the disease. Studies are thus needed, using population based cohorts in contrasting communities, to provide basic data for planning primary and secondary prevention of disability among the elderly. This would involve the utilization of cohorts followed from a CVD-free stage, at which time risk factors are measured in a standardized fashion and disease end-points are subsequently recorded in a standardized fashion. Continued follow-up is then carried out to measure the type of care received, disabilities and handicaps ascribable to the disease, and the social and economic support systems available and used by the cohort members.

In both developed and developing countries little is known of the occurrence of disabilities in the elderly. In order to plan for changes in delivery of health services for aging populations and to examine the economic and social implications for developing countries, it is necessary to have information on the health status of the elderly and the consequent loss of autonomy which may possibly accompany morbidity. It is also important to have knowledge of what social (family and community) structures are in place to intervene in the chain of events that lead persons with various impairments to transit to disability and handicap status.

Intervention to prevent or retard the transition from impairment to handicap will depend upon the natural history of the handicapping process as well as an understanding of the risk factors and the other variables involved. Ideally studies on the disability process should be longitudinal, following individuals from development of disease through the chain of consequences. Much information can also be obtained about the disability process from cross-sectional surveys of aging populations where individuals with various combinations of impairments, disabilities and handicaps are measured using standardized instruments to determine presence and degree of each of the three stages. Measures of various intervening variables at each stage are also made, along with attempts to derive a retrospective history of the disease or accident process which led to the impairment. Intervening variables include: sociodemographic information on the index case and members of his family, economic and environmental variables in the household, past and present access to, and utilization of, health services and the presence of community support services. The studies need to be population based with perhaps oversampling of certain of the elder age groups.

Three aspects of research on aging, all of which have recently been cited by WHO at recent meetings or working groups on aging as priority items, have been mentioned above. Other important research areas in aging, also of direct concern to WHO, have not been cited; for example, dementias and nutritional problems in the elderly.

Several WHO-related projects have characteristics which could, with collaborative efforts, lend themselves to addressing some of the issues mentioned above.

The first three of these projects deal with chronic degenerative diseases in adult populations, mostly in developed countries. These are cross-national, usually attempting to look at ranges of risk factor prevalences and disease incidences in countries with different cultural and socioeconomic backgrounds. Some are observational in nature, while others include interventions of certain kinds on all or part of the populations under observation.

The first of these projects is carried out by the WHO Regional Office for Europe and is located at the WHO Collaborating Centre for Research and Training in Cardiovascular Diseases at the Institute of Clinical and Social Medicine, University of Heidelberg. This project, code-named ERICA, has as a main aim the collection and central analysis of available data from national and international collaborative studies in Europe on risk factors for coronary heart disease and the incidence and prevalence of coronary heart disease (CHD). Studies will be examined to produce a risk map for CHD for Europe and to predict trends in CHD on the basis of changing risk factor levels. Participation is based upon a well-defined population group for each study, standardized methods of investigation, the submission of individual data, and the original survey not having been started before 1970. Pooling of data takes place only when acceptable limits of quality control have been adhered to.

Thirty-six European centres participate corresponding to 30 studies in 18 countries. The present data base is about 160 000 persons with about 10 000 persons above the age of 60 at the outset. Several centres have now 15 years follow-up which would raise the number of persons followed to age over 65 years to about 25 000. Not all studies provide follow-up data on risk factor changes or monitor CHD mortality. In addition to the standardized measures of risk factor and CHD events, a wide range of sociodemographic data is available for each study. Measures of functional health (disabilities or handicaps) are not usually measured but there is the possibility of these measures being added, both at the risk factor follow-up examinations and as a further follow-up to those who have suffered from non-fatal CHD. Addition of such measures, particularly in the older age groups, in the fourteen centres that are still active could provide valuable information on the relationships between risk factor levels for CHD and disabilities and handicaps resulting from the disease and its risk factors.

A second WHO-related project of cross-national significance is the MONICA study, MONICA being an acronym for Monitoring of Trends and Determinants in Cardiovascular Diseases. This study involves 40 centres in 26 countries, for the most part industrialized nations in Europe, North America and the Pacific Region. The centre in Beijing China is perhaps the only one that could be regarded as being from a developing country.

The main objective of the study is "To measure the trends in cardiovascular mortality and coronary heart disease and cerebrovascular disease morbidity and to assess the extent to which these trends are related to changes in known risk factors, daily living habits, health care, or major socioeconomic features measured at the same time in defined communities in different countries". The target population has been originally set at 25-64 years, although many centres have extended the age group to include 65-74 years in order to observe more CHD and stroke events. The four main measures needed to address the main objective are:

1. Incidence rate (fatal and non fatal attack rates of CHD and stroke)
2. Case fatality rate (fatal attack rate/incidence rate)
3. Risk factor levels (using a multivariate score)
4. Medical care (a not yet determined scoring system).

Incidence and mortality are measured continuously by monitoring within the defined population at each centre over a 10 year period while risk factors are measured in population surveys at three intervals during the ten year period. The ten year monitoring period began for most centres during 1983 or 1984, and all centres have completed their initial surveys of risk factor levels. About 1600 persons are screened for risk factors in each centre. Some centres will follow the screened persons for morbidity and mortality and for re-screening, while most centres will not attempt individual linkage of risk factor measurements over time with CHD or stroke events.

In addition to the standard risk factor measures; smoking, blood pressure, serum cholesterol, weight and height, many centres have included optional measures of other potential risk factors for which standardization of measurement is attempted.

These include:

1. Psycho-social factors: 16 centres
    (a) social network/social support
    (b) life stress, vital exhaustion, sleep disturbance
    (c) socioeconomic, cultural, political
    (d) social mobility
    (e) type A behaviour patterns
    (f) job characteristics
    (g) health knowledge and attitudes
2. Physical activity 20 centres
3. Surveillance of dietary habits 15 centres
4. Vitamin study-level in blood 6 centres
5. Medical drug usage 12 centres
6. Follow-up for cancer at major sites 19 centres

It could also be envisaged to add questions on disabilities and handicaps to the population-based surveys, or to attempt a continued follow-up for disability measures for those non fatal cases of CHD and stroke identified in the event surveillance. This would allow measurement of relationships between various types of risk factors to subsequent disablement followed over a five to six year period (the remainder of the 10 year follow-up period) and to cross-nationally examine relationships between risk factors, development of CHD and stroke events, and subsequent disabilities. Follow-up of disabled cases could be extended beyond the 10 year cut off point for CHD and stroke events.

INTERHEALTH is an integrated programme for community control and prevention of noncommunicable diseases, it has close ties with a strictly European group, CINDI, Countrywide Integrated Noncommunicable Diseases Intervention Programme. These programmes have, as goals, prevention and control of common risk factors for a group of noncommunicable diseases in the total community utilizing a wide range of intervention strategies. The programme will include special components for elderly populations. As yet most of the risk factors being considered are those found related to specific noncommunicable diseases, and the disease end points are structured to disease incidence and mortality rather than functional limitations and measures of autonomy loss.

In addition to fourteen European industrialized countries and two North American industrialized countries, ten developing countries from various regions of the world are also included in INTERHEALTH. Thus intervention programmes will be targeted at groups in relationship to environment, life style, and life span transition.

At present the modulized nature of the programme allows for non-disease specific measures.

One important aspect of the INTERHEALTH programme will be the use of data from the demonstration projects, projects such as ERICA, and (to some extent) MONICA, to develop sets of simulation models for testing different scenarios relating to mixes of prevention and control strategies in specific country situations. This will allow evaluation of the cost effectiveness or impact of various community intervention strategies.

The development of biologically realistic forecasting and planning models for chronic diseases in elderly populations is a difficult task because of:

1. the multifactorial nature of most chronic diseases;
2. differing lag times between risk and disease onset;
3. changing risk factor-disease onset relationship with age, particularly in later age ranges;
4. competing risks between diseases;
5. age selection of the population with respect to specific disease outcomes.

A WHO Working Group on risk assessment modelling was initiated in 1984 to deal with the above modelling issue. Subsequent to the first meeting the Center for Demographic Studies at Duke University was appointed as a WHO Collaborating Centre for Risk Assessment in Noncommunicable Diseases. A state of the art summary of forecasting and planning models for chronic diseases has recently been produced by Professor Manton and Mr E. Stallard of this Center, and is to be published by Charles Griffin as a Statistical Monograph under the title "Chronic Disease Modelling: Measurement and Evaluation of the Risks of Chronic Disease Processes".

In addition to modelling and projecting disease processes there is also a need to model health service delivery systems and develop measures of social and economic costs of morbidity, disability and mortality. A future Working Group meeting will deal with these issues.

In both developed and developing countries surveys have been carried out using either the WHO ICIDH or precursors or variations of it. Three WHO related population-based surveys used a precursor of the current ICIDH where there was the possibility to validate the presence and severity of impairments and disabilities, by means of clinical examination and extended history-taking on disease and impairments, and by means of functional tests carried out by trained personnel. In all three studies; Belgrade, Yugoslavia, 1974, Indonesia, 1978 and Orissa State, India, 1980, the questionnaires were administered or reviewed by medically qualified personnel. The sample size in Belgrade was 4560 persons aged 35-54, while the Indonesia and Orissa surveys were both approximately 22 500 persons and covered all ages. A wealth of socio-economic, health utilization and social and community support data were also collected. In Belgrade, hospitals and health centres were visited to verify utilization.

Findings from these three surveys were used in advising China on a large scale disability survey currently in the field.

The study on disability in China is a three stage study:

First stage - A representative probability sample of the Chinese population of size 1 250 000 will be screened for functional disabilities - both mental and physical. It is expected to identify disabilities in 125 000 persons.

Second stage - Each person with some form of functional disability will be examined by a team of physicians for preceding impairments, severity of disability, prognosis with respect to autonomy status and recommended treatment. Previous access to and use of health services will also be queried.

Third stage - A selection of six of 29 provinces within which randomized counties will use preventive and rehabilitation services delivered through PHC (WHO Rehabilitation guidelines), while other centres will use usual services. (4) Follow-up surveys will be carried out to measure changes in disability rates in the PHC delivered services and in the other services.

Because of the relatively old population in China and the increasing rate of disability with age, it is expected to have access to information from large samples of disabled persons at ages beyond 65 years, along with the antecedents to disability and its consequences.

This report has raised several issues dealing with aging populations of concern to WHO and other international and national organizations.

It has been shown that studies already operational under WHO auspices are capable of addressing, fully or partially, these issues with the collaboration of scientific groups who can supply the necessary skills and funds to make use of the study frameworks and international collaborative efforts already in existence.

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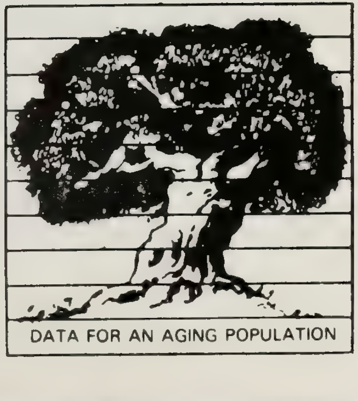
Session S

Can Local Experience Be Applied to National Surveys?



DATA FOR AN AGING POPULATION

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COLLABORATING RESEARCH IN NATIONAL-BASED AND COMMUNITY-BASED STUDIES

Daniel J. Foley and Laurence G. Branch

INTRODUCTION

More nationally and locally representative information is being collected longitudinally on older populations than ever before. These data will be used to address both broad and specific trends in health. Nationally, these include the National Long Term Care Survey (Macken, 1986) the Longitudinal Study on Aging (Kovar, 1987), and the NHANES-I Epidemiologic Followup Survey (Madans, Kleinman, Cox, et al., 1986). On the community level, the NIA sponsored "Established Populations for Epidemiologic Studies of the Elderly" (EPESE) represent current prospective studies of older populations (Huntley, Brock, Ostfeld, et al., 1986).

The objectives of these longitudinal studies are to facilitate a better understanding of mortality and morbidity after the age of 65. Over 60 percent of the 2 million deaths that occur annually are among those age 65 and over and roughly one-third of health expenditures are consumed by this age group, much of it in the last year of life. Information about these circumstances are urgently needed to help shape policy for the "aged boom" occurring now among those over age 80 and in the near future as the large number of people in the "baby boom" generation move into the older age brackets.

Major endpoints to be specified over the course of both the community and national studies are: the causes of death; the history of hospitalizations including diagnoses and procedures; the history of nursing home care including the level of care and length of stay; and the repeated assessment of physical and cognitive function. The quality of the endpoint data will depend on the methods used for surveillance, ascertainment, and assessment as well as the availability, reliability, and validity of that data. The purpose of this paper is to briefly review data sources available and used in these national and local surveys and selected topics that can be addressed by these data.

SOURCES

Most longitudinal studies now use the National Death Index to compliment or serve completely as the screen for deaths and the means for acquiring death certificate data. In the EPESE, copies of the death certificates are obtained through local channels on as many participants as possible. Death certificates from all participating sites are reviewed and coded by a single nosologist to establish the underlying cause of death.

Data on hospitalizations, nursing home stays, and physical and mental function address morbidity in limited ways. One source of hospitalization information is the Medicare Part A utilization data collected by the Health Care Financing Administration. These data provide diagnostic and surgical information standardized to both the International Classification of Diseases-9th Edition (ICD-9) as well as the more recent Diagnostic Related Groups (DRG).

All four studies mentioned here are in various stages of linking into this information and the potential for using the Part B ambulatory care data are being investigated. Some of the EPESE locations have also made arrangements to screen area hospital admissions and nursing homes to support the local area surveillance program for data on these endpoints.

The association between prevalent and incidental diagnostic data and functional health can be measured through repeated assessment of physical and cognitive function. Prognostic information will likely evolve from this combination of information, particularly in analyses focused on the recovery from illness and outcome studies of multiple-condition profiles. Figure 1 provides a schematic overview of the items included in the annual physical functioning assessment in EPESE. Many of these items, particularly the activities of daily living, are common to the national surveys as well.

If possible, EPESE study participants traced into nursing homes are asked to continue participation (via self or proxy) in scheduled interviews if consent is provided by both the facility staff and the participant or next-of-kin. In these national and local studies, the primary source for identifying nursing home stays is through self and proxy reporting of the event. As mentioned above, the facility is then contacted directly for information regarding dates of admissions and discharges as well as level of care provided.

Cognition is generally assessed through a short mental status questionnaire (MSQ). In the EPESE we use a modified Pfeiffer MSQ (Huntley, Foley, White, et al., 1985). This assessment takes place only in the scheduled face-to-face interviews which occur every three years. The EPESE are now entering the sixth year of followup and so this will be the third cognitive assessment, the others having been done at baseline and in the third year of followup. With the exception of these face-to-face interviews annual contacts are made by brief phone calls to ascertain hospitalizations, nursing home stays, physical function, and a few other general health questions. In the national surveys, contacts are made less frequently and cognitive assessment is not always available.

SELECTED TOPICS

Some of the broad topics to be addressed by these and other studies of older populations include the last years of life, the recovery from illness, and the need for long-term care support. An NIA- sponsored study entitled "The Survey of the Last Days of Life" was recently completed on a sample of 1,200 decedents in Fairfield County, Connecticut (Brock and Foley, 1985). Through interviews with the decedent's next-of-kin, information was gathered on the lifetime history of conditions and circumstances surrounding death. Information on the last year of life from this study and the longitudinal studies mentioned here will provide a better understanding of the magnitude of sudden versus lingering death, the course of functional health (mental and physical) in the years just prior to death, the presence of pain or discomfort, costs, and in general the quality of death and dying in the older ages.

Issues involved in the recovery from illness in the older years include the type of illness, the age and sex of the patient, functional status, existing conditions and diagnoses, and the necessary level and duration of followup care. Concern is growing over the use of life-sustaining technologies and the implications for unwanted aggressive medical treatment or conversely financial barriers to such treatment in the event of catastrophic illness (U.S. Congress, 1987).

Long-term care, while primarily thought of as nursing home care, could be viewed more generally as the daily support offered by one individual to maximize the quality of life for another. In nursing homes, an organized staff of professionals and others provide care for the needs of frail residents whereas in the family setting, the frail person is cared for by one (often a spouse) or more family members. These two settings illustrate the basic difference between formal long-term care and informal long-term care, and the extent of these two types of care is one way of addressing the burden of morbidity in old age (See Figure 2). Roughly half of those age 85 and over (1.2 million people) currently receive long-term care support. The population age 85 and over is projected to double as early as the year 2000 and this could mean another 1 million people requiring long-term care support over the next 13 years. Clearly, we need to better understand the determinants of the need for and use of long-term care.

CONCLUSIONS

Assessing the quality of life in the older ages is perhaps the panoramic topic for which empirical data are sought and gathered in many longitudinal studies of aging. And if the goal of the medical care system is to improve the quality of life in the older ages, then the definition and means for measurement of "quality" must be clearly stated if we hope to mark progress over time. Measures of physical and mental well-being of the older individual is central to research on this concept of quality. Ideally, empirical data would include the onset, duration, and outcome of disease and conditions influencing the physical, mental, and even the economic well-being of an aging individual. Such comprehensive data would allow for an evaluation of the current and projected progress of the medical care system in responding to the burden of age-dependent morbidity. In the absence of such ideal and comprehensive data (due to the size, means, and costs of the design) information on the last years of life, the recovery from illness, and the need for long-term care support will provide fundamental data needed to plan how we will meet and finance the future needs of our ever growing older population. The longitudinal data from these studies will provide some of the resources for addressing these issues.

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FIGURE 1

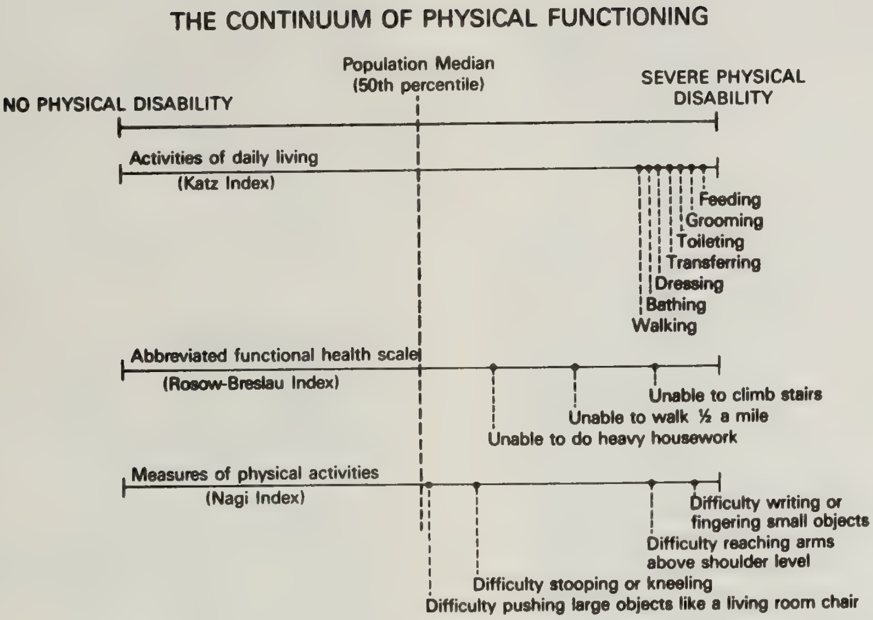
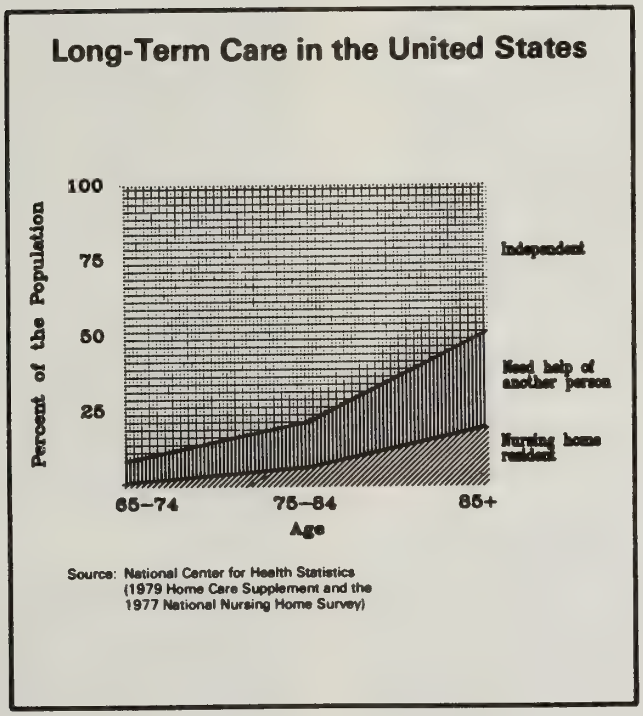

THE CONTINUUM OF PHYSICAL FUNCTIONING
Population Median
(50th percentile)
NO PHYSICAL DISABILITY
SEVERE PHYSICAL DISABILITY
Activities of daily living
(Katz Index)
Feeding
Grooming
Toileting
Transferring
Dressing
Bathing
Walking
Abbreviated functional health scale
(Rosow-Breslau Index)
Unable to climb stairs
Unable to walk ½ a mile
Unable to do heavy housework
Measures of physical activities
(Nagi Index)
Difficulty writing or fingering small objects
Difficulty reaching arms above shoulder level
Difficulty stooping or kneeling
Difficulty pushing large objects like a living room chair

FIGURE 2



Source: National Center for Health Statistics (1979 Home Care Supplement and the 1977 National Nursing Home Survey)

LINKING RECORDS IN MANITOBA

Jana M. Mossey, Medical College of Pennsylvania

Occasionally the opportunity exists to link data from several sources and thereby to address questions that could not be considered with any of the data sets in isolation. In the mid 1970's, such an opportunity existed in Manitoba, Canada. We had become interested in the use of health services by the elderly. Of particular concern were questions regarding whether the observed disproportionate high consumption of health services by older individuals was a characteristic of the group, whether the increased use of services was an inevitable consequence of growing older or whether there was one definable group of older individuals who, over time, were consistent high users of both the physician and the hospital and another whose use was limited and essentially unchanging as they aged.

The purpose of this paper is to describe our experiences in linking several distinct Manitoba data files to create the information base that has been used to address these and other questions. I will begin with a brief description of the salient aspects of the data bases and the linked records that have been developed. I will then consider some of the specific types of research questions that we have been able to address with the linked data files. Last, I will discuss the implications of this work for exploitation of similar data sets within the U.S. context and, specifically, at the national level.

The Manitoba data files that were available to us are listed in Figure 1. The provincial government maintains a universal health insurance program in which virtually all health services are supported through tax based revenues and are free of out-of-pocket costs to the consumer. Physician and hospital services have been insured since 1969 and nursing home and home care services were insured in 1973 and 1974 respectively. To administer the insurance program, the Manitoba Health Services Commission (MHSC) maintains a master registry file and physician, hospital and personal care home service claims files. The Provincial Office of Continuing Care maintains a data base pertinent to the home care program. These files provided information on health service use. In addition, the raw data files from the Aging in Manitoba Survey that was undertaken in 1971 to identify the needs of older residents were available. The final data source was the mortality tapes maintained by the Vital Statistics Division of Statistics Canada.

The (MHSC) master registry is a registry of the provincial population. Comparison with the national census data show only about a 2% discrepancy between the two sources of population estimates. The Master Registry is organized by family with each family receiving an identifier and family members uniquely distinguishable by sex, birthdate and initial, changes in family identification number due to marriage are documented. From 1969 through 1974 the Master Registry was continuously updated with cross-sectional snapshots recorded at 6 month intervals. Following 1974, the registry was updated at 24 month intervals.

Figure 1: Source Data Bases

Manitoba Health Services Commission (MHSC)

- Master Registry
- Physician claims files
- Hospital claims files
- Personal care home (PCH) claims files

Office of Continuing Care

- Home care file

Aging in Manitoba Survey in 1971

Statistics Canada

- Mortality file

The specific claims files exist for the purposes of reimbursement and monitoring the respective health services. The physician claims files contain a record of each reimbursable physician service received irrespective of service location. The provider is responsible to submit the service claim. Patient MHSC number, visit date, codes describing services and diagnoses pertaining to the reason for visit are reported. In addition, physician identification information is included.

The hospital claims files contain summary data submitted after a hospital discharge. Individual MHSC identification number, admission and discharge dates, hospital location, ICD-A surgical and discharge diagnoses are coded as well as occurrence of death. The personal care home files document each PCH admission with comparable identification and service use information included.

These claims files are maintained separately. They are organized chronologically, by individual for each calendar year. Extensive assessments of the quality of the data indicate they are complete, valid and reliable. Moreover, because of the comprehensive nature of the insurance program and the coverage of services obtained both in and out of province, they document virtually all health services obtained by an insured individual. The home care files contain similar information although no MHSC number.

In addition to sociodemographic information, the Aging in Manitoba Survey files contain cross-sectional data for each respondent on health status, physical function, social contacts, life satisfaction and need for and use of community services. Those surveyed constitute a sample of residents 65 years and older that was drawn randomly from the December 1970 MHSC Master Registry tape. The final interview sample consisted of 4805 individuals of whom approximately 3500 were community residents and the remainder institution dwellers. Importantly, at the time of administering the interview, the individual's MHSC number was obtained and consent was granted by the interviewee for future linkage of the survey with the health care claims data.

In 1978 a grant was received from Health and Welfare Canada to develop the Manitoba Longitudinal Study on Aging. Our objective was to construct longitudinal files for each survey respondent that contained the interview responses, a summary record of health service use for the years 1970-1977 and occurrence and date of death. The MHSC data were released with the stipulation that no names could be used at any point in the research process. Essentially, therefore, data linkage had to be accomplished with the MHSC number, birthdate, sex and first initial as the common identifier.

To develop the longitudinal file we were confronted with three initial tasks. First, we had to obtain a match between the Aging in Manitoba Survey and the MHSC Master Registry. Second, we were required to track coverage status of each matched subject through the 8 study years. Last, we needed to develop a workable method for summarizing the extensive health care claims data. The Master Registry was critical for the first two tasks. A match between the survey respondents and the registry was achieved for 4709 individuals (98.2%) of the survey sample. Documented eight year follow-up occurred for 94% of the matched sample yielding an overall follow up rate of 91%. The independence of the Master Registry file from the claims data, the regular cross-sectional snapshot files, the cross referencing of individuals when a change in registration number occurs and the presence of cancellation codes that indicate death or move from province were critical features that permitted this degree of tracking success.

While the raw MHSC claims files had the advantage of being complete, they existed in an unusable format. Theoretically, for example, during the eight year period an individual could have no or few claims for physician services while another individual could have a claim for each of the 2820 days. Although not actually occurring, the number of physician claims filed for individuals over the eight years did range from none to over 800 and hospital use varied across individuals from between no use to 31 discharges.

Summarization procedures were developed to yield a uniform record for each individual that documented the type, frequency and locations of services received as well as the specific nature and magnitude of the problem associated with the service. The major utilization indices are shown in Figure 2. They were summarized over 12 month intervals to form a record for each individual with 8 replicated measures.

Figure 2: Summary Utilization Indices

Ambulatory Physician Services

- Number of ambulatory physician visits during the interval
- Number of months during the interval in which an ambulatory physician visit occurred
- Number of unique diagnoses (ICDA - 8th Revision) reported during the interval
- ICDA (8th Revision) three digit code for the three most frequently occurring diagnosis during the interval
- Number of ambulatory services (e.g. Lab, x-ray) reported during the interval
- Number of ambulatory physician visits for reported chronic disease diagnoses

Hospital-Based Services

- Number of admissions to an acute care hospital during the interval
- Number of days in an acute care hospital during the interval
- ICDA (8th Revision) four-digit code for most frequently occurring hospital diagnosis
- Operation code (ICDA - 8th Revision) for the operation with the highest Hernia Equivalent
- Number of admissions to a chronic care hospital during the interval
- Number of days in a chronic care hospital during the interval

The health care use and survey data contained in the Manitoba Longitudinal Study on Aging have been used to address a variety of issues. These are summarized in Figure 3. They include descriptive analyses of the distribution of health services use, the assessment of consistency over extended time periods in health care utilization, the evaluation of the consequences of different patterns of use, the epidemiology of self perceptions of health and the development of claims based measures of health status. In each case, the availability of health care claims data, documentation of mortality and survey responses permitted the evaluation of more complex and substantively interesting questions than if only one type of information had been available.

Figure 3: Studies using the MISA data

1. Users and nonusers of health care services
2. Nursing home utilization
3. Chiropractic users
4. Subjective and objective health status
5. Consistency of utilization over time
6. Measurement of health status using insurance claims

Drawing on the experiences and methodologies used in the tracking, linkage and summarization procedures for the Manitoba Longitudinal Study on Aging, a second series of linking procedures have been used to develop files based exclusively on the MHSC and Vital Statistics administrative data. Retaining the restriction on use of names for identification and linkage purposes, longitudinal files of stratified random samples of the provincial population and cases who have experienced an event such as a surgical procedure and unexposed controls have been developed. Specific examples of the questions that have been addressed with the linked data from these sources are shown in Figure 4. As seen here, information has been particularly useful in investigation and evaluation of common surgical procedures.

Linking the Manitoba data files have been particularly successful and productive. While certain aspects of the Manitoba source files and the provincial health insurance program are unique, similar possibilities exist and are being exploited in the United States. Most notable, the Medicare data have many features that are similar to the Manitoba Health Services Commission data. A master beneficiary file exists that includes 97-98% of the eligible population 65 years of age and older. Presumably cross-sectional files have been saved and can be used to track the coverage status of individuals over time. Moreover, the master beneficiary file is being made available to researchers for use as a sampling frame and a 5% sample of continuously enrolled individuals is being followed over time with longitudinal histories being developed.

The Medicare data files, however, have several critical limitations. First, only chronically disabled individuals and those over 65 years of age are included in the program. A population registry in the United States similar to the MHSC Master Registry that spans all ages does not exist. The closest approximation, the Social Security Administration Beneficiary file is limited by selective under registration.

Figure 4: Studies using the linked MHSC Files

A. Outcomes of common surgical procedures, including
    1. Tonsillectomy/adenoidectomy
    2. Hysterectomy
    3. Cholecystectomy
    4. Hip replacement
    5. Prostatectomy
    6. Coronary artery bypass graft surgery
B. Small area variation
    1. Meaning of rate variations across a number of surgical and diagnostic procedures
    2. Physician supply and workload, patient utilization
C. Physician behavior
    1. Surgical workload and turnover, 1974-78
    2. Overall workload, 1978-82
    3. Variations in physicians' hospitalization practices

Second, although the Medicare claims for physician and hospital services are submitted with an associated health insurance identification number for the individual and the construction of longitudinal files is possible, the claims files suffer from underreporting. Not all services are eligible for reimbursement and so claims for these are not filed. Individuals who have not reached the deductible for reimbursable physician services may simply not file a claim until a substantial bill has been generated. Thus, physician services of infrequent users may not be reported. Cost ceilings exist for many services and once exceeded there is no incentive to submit a claim. Increased reliance on the HMO where reimbursement is on a per capita rather than a fee for service basis is also likely to adversely affect the degree to which the Medicare system accurately represents an individual's use of health services. Service underreporting, especially since it is not well documented, is particularly regrettable. Indeed, a critical aspect of the work with the Manitoba data has been the confidence in the accuracy and completeness of the claims data.

A critical issue, in addition to the logistics of matching and data linkage, has been related to confidentiality and informed consent. The Manitoba Longitudinal Study on Aging claims data and survey response files linkage would have been impossible if the survey respondents had not explicitly given signed consent for subsequent research and linkage at the time of the survey. Specific, but open ended consent statement authorizing subsequent merging of study data may be an important addition to ongoing national studies such as the Health Interview Survey and the HANES Surveys.

Although not entirely free of potential problems, our experiences have demonstrated the advantages and usefulness of linking existing data files for research purposes. Several characteristics have emerged as particularly relevant in assessing whether linkage of several data files would be productive. In concluding, these are enumerated below:

1. The source data bases should be reliable, valid and complete.
2. The reference population should be completely enumerated and for each individual there should be a unique and permanent or trackable identifier common to the distinctive data sources.
3. The registration system should be independent of any specific activity such as a physician or hospital visit; it should document change in coverage status and files should be periodically saved.
4. Mechanisms for resolution of issues related to confidentiality and to the linkage of data from surveys must have been established. This is especially important even if individual names are not required but are merely included on the source data files.

If health care claims data are to be used several additional characteristics of the data source are recommended.

1. A claim should be filed for all services received whether reimbursed or not
2. Audit procedures should be established that guard against under or over reporting and/or incorrect coding and data entry
3. Claims should be filed by the provider with some incentive for complete reporting
4. Claims should contain, at a minimum, individual and physician identification information, date and type of service, and health problem associated with the service.

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Item Nonresponse And Response Bias In Mixed Mode Surveys

Donald J. Brambilla, Sonja M. McKinlay, and John B. McKinlay
American Institutes for Research

With the rapid aging of the American population, there is a need for reliable data with which to inform health policies that affect the elderly. Health studies have traditionally relied on the face-to-face interview to gather such data but this approach has increased dramatically in cost, making it much less attractive. More important for studies of the elderly, subjects with such functional limitations as impaired hearing or speech may not be able to respond in a face-to-face interview (1). Because the prevalence of these and other functional limitations increases with age, a face-to-face interview survey of the elderly is likely to obtain a biased sample. Moreover, fear of strangers, especially among elders in inner cities, will reduce response in these areas, further increasing the risk of response bias.

Surveys by either mail or telephone face similar difficulties, albeit with different functional limitations. A mixed mode approach, however, provides a solution to these problems. In a mixed mode survey, two or more methods are employed to gather data. Generally, the second, and if necessary the third, mode is employed to gather data from nonrespondents to the first. Response rates as high as those obtained in face-to-face interview surveys, and higher than those of surveys by either mail or telephone alone, are frequently obtained with this approach (2-6). Response to the followup modes can also reduce response bias with respect to socioeconomic (6,7) and health traits where functional limitations prevent subjects from responding to the first mode in a survey (1). For example, elders whose visual impairments prevent them from responding to a mailed questionnaire could respond to followup telephone interviews.

The face-to-face interview survey is widely held to produce the highest response rates and the most complete and reliable responses. It is thus appropriate to consider the reliability of the data gathered in mixed mode surveys. This paper focuses on two areas of particular concern. First, do individuals change their answers when surveyed by different modes? Second, do incomplete responses bias the results of the survey? Item nonresponse is a common problem in surveys. Typically data are assumed to be missing at random but this critical assumption is rarely validated. If data are missing nonrandomly, inferences from the survey could be compromised (8).

When such problems are encountered, many health researchers think of accessing medical records or other data sources to supplement survey results -- an approach that is attractive but often not feasible. This papers takes a different approach, employing what amounts to a resurvey of respondents.

The data employed were collected in a study of the health of Massachusetts women in their middle years (6). The study began with a mixed mode survey that employed mailed questionnaires as the first mode of contact. Nonrespondents to two questionnaires, plus an intervening postcard reminder, were then interviewed by telephone, yielding a response rate of 77%. Among the 8,050 respondents, 5,927 (73.6%) of the women completed a mailed questionnaire and 2,123 (26.4%) were interviewed by telephone.

This mixed mode survey was the baseline (T_0) survey for a longitudinal study of health and the menopause (9) Respondents at T_0 were recruited for the longitudinal study if they had menstruated in the prior three months and had an intact uterus and at least one ovary. A total of 2,741 premenopausal women were identified, of whom 2,568 (93.7%) were successfully recruited, including 1,954 (76.1%) who had answered a mailed questionnaire at T_0 and 614 (23.9%) who had been interviewed by telephone at T_0. The longitudinal study consisted of six telephone interviews at nine month intervals (T_1, T_2, etc.). Thus, some subjects answered a mailed questionnaire at T_0 and were subsequently interviewed by telephone, while the remainder were interviewed by telephone on all occasions. As described below, this difference in mode of data collection can be profitably exploited to investigate the problem of mode-related response variation and the problem of nonrandom item nonresponse.

MODE-RELATED RESPONSE VARIATION

One worrisome aspect of mixed mode surveys is that respondents to the initial and followup modes usually answer some, but not all, substantive questions differently (2,3,4,6,7). In the baseline survey described above, subjects who answered a mailed questionnaire were much more likely than subjects who were interviewed by telephone to report recent health-related consultations with friends or relatives and recent incidences of any of seven common physical symptoms (6). Those who responded by mail, however, were no more likely to report that they had ever been diagnosed as having any of eight chronic conditions or that their health had recently restricted their normal activities. They were only slightly more likely to report ever having experienced chemotherapy, radiation therapy or any of eight gynecologic surgeries.

Two sources of variation could account for these results (6). First, the results could reflect problems arising from the survey modes themselves. For example, biased recall of such relatively minor events as common physical symptoms could account for the low frequencies with which they were reported by telephone. The results, however, could just as well reflect characteristics of the respondents to each mode. Mode of response is self-selected in the sense that subjects were interviewed by telephone only after they chose not to respond to the mailed questionnaires. Thus, characteristics of the respondents could be confounded with response mode.

A single cross-sectional data point, such as T_0, is insufficient to investigate the relative contributions of these two explanations. One promising approach to the problem would be to resurvey respondents, allowing response mode to vary longitudinally so that variation of responses between modes within subjects could be examined. Some of the questions from the baseline study were repeated in the longitudinal interviews. The probabilities that responses to each question changed between T_0 and T_1 were therefore compared across baseline response modes. These comparisons were stratified on responses at T_0 because the probability that a response changes may depend on the initial response itself. Response to ten questions were examined, including seven on recent common symptoms, two on consultations and one on restricted activity. Included among these are the questions that produced the large mode-related response differences at T_0 that motivated the concern with mode-dependent data quality.

The subjects in this survey were interviewed at nine month intervals but these questions referenced the two weeks prior to interview. Some variation of responses between interviews is therefore to be expected, regardless of the sequence of modes employed. The point of the comparison of responses at T_0 with those at T_1 is to search for additional variation that is associated with the sequence of modes employed. While the intent here is to attribute any such additional variation to the limitations of one or both response modes, a second potential source of this variation must be considered: because of the confounding of respondent characteristics with mode of response at T_0, subjects who responded to one baseline mode might be more likely than subjects who responded to the other to change their answers for reasons other than the sequence of modes employed. This would imply, however, that responses should vary more in one group than the other even when mode of response does not change between interviews.

The probability that responses to each of the ten questions changed between T_1 and T_2 were compared across baseline response modes, after stratifying on response at T_1. Mode of response did not vary between T_1 and T_2, so any differences detected in these comparisons would be attributable to differences between the respondents themselves. Conversely, if rates of response variation between these interviews appear to be similar in the two groups, then respondent characteristics that affect rates of response variation probably are not confounded with baseline mode of response.

Among the 20 comparisons of response variation between T_1 and T_2, only one relatively small difference ($p<0.05$) was detected (Table 1). Given the multiple comparisons problem, a single difference can be attributed to chance variation. It therefore appears that the two groups of respondents are equally likely to change their responses between two interviews conducted by the same mode.

The 20 comparisons of response variation between T_0 and T_1 also turned up only one relatively small difference (Table 1). This single difference among 20 comparisons is probably also attributable to chance variation. It can be inferred that, had subjects who answered a mailed questionnaire at T_0 instead been interviewed by telephone, their answers to these ten questions would have remained about the same. Thus, the response differences in this mixed mode survey probably are not caused by characteristics of the data collection modes themselves but reflect characteristics of the respondents to each mode.

NONRANDOM ITEM NONRESPONSE

One goal of the baseline survey was to obtain cross-sectional information about the health status of a community sample of women in their middle years. Item nonresponse, however, varied with health status and the resulting nonrandomly missing data could bias inferences about the health status of the target population.

To illustrate the problem, consider counts of missing responses as a function of self-assessed health, which is the respondent's rating of her own health compared with that of her peers. This measure has been shown to be a reliable indicator of health status (10-12). Table 2 presents the distributions of counts of missing responses among subjects who responded by mail. These distributions are standardized to the distribution of education among subjects who assessed their health as the same as that of their peers. Education is associated with self-assessed health (6) and is probably also associated with item nonresponse. Obviously, the distributions include only the subjects who both assessed their own health and reported their education, but the majority did both (97.1% by mail, 98.1% by telephone). The counts of missing data do not include 53 items in branch patterns because the number of such items that should have been answered varied widely among respondents.

It is clear from Table 2 that counts of missing responses to the 69 health-related items varied with self-assessed health. Both the probability that item nonresponse occurred at all and the counts of missing responses tended to be highest among those who assessed their health as worse than that of their peers and lowest among those who assessed it as better. In contrast, counts of missing responses to the 18 socioeconomic/behavioral items, excluding education did not vary with self-assessed health (Table 2). Counts of missing responses in telephone interviews were generally much lower than on mailed questionnaires and they were unrelated to self-assessed health. The important point, however, is that, among roughly three quarters of the respondents to the baseline survey, the number of missing responses to health-related items varies with health status.

The results reflect underlying associations between self-assessed health and rates of item-specific nonresponse to some key health-related items, including those exploring chronic conditions ever diagnosed, surgical history, and recent symptomatology (13). Thus, the nonrandomly missing data could compromise inferences about these important aspects of health status and their correlates in the target population. It is important to note, however, that these data are missing nonrandomly with respect to the marginal distribution of health status in this population. They could well be missing conditionally at random, given health status. Then, if self-assessed health is a sufficiently accurate surrogate for health status, the distributions of health characteristics could be weighted according to the distribution of self-assessed health to provide a more accurate picture of the target population.

Validating this approach requires estimates of the unobserved data. To the extent that health status at one interview can predict health status at another, data from T_1 can provide the needed information. Item-specific rates of nonresponse at T_1 were extremely low (<0.5%), even among subjects with large amounts of missing data at T_0.

Consider, for example, recently experienced common symptoms reported by subjects who had answered a mailed questionnaire and were then recruited for the longitudinal study. Among the 1,854 subjects who answered all seven of these questions at T_0, the number of symptoms reported at T_1 (0, 1-2, 3-7) is closely associated with the number reported at T_0 (X^2=371.5, df=4). Subjects with missing symptom data at T_0 tended to report more symptoms at T_1 than subjects with complete T_0 symptom data (Table 3). Presumably then, they also would have reported more symptoms at T_0, had they answered all seven questions.

In addition to estimates of the unobserved data, a measure of the relationship between self-assessed health and other aspects of health status is needed to validate the approach to missing data considered here. This measure must include subjects with missing T_0 health data. Such a measure can be obtained from the relationship of self-assessed health at T_0 to health status at T_1 (nine months later), which should be a reasonable surrogate for the relationship at T_0 of self-assessed health to health status. Consider, again, recently experienced physical symptoms. Self-assessed health at T_0 is closely associated with symptomatology at T_1 (Table 4), and presumably with symptoms experienced at T_0.

Given the close association of symptoms at T_1 with symptoms at T_0, the number of symptoms experienced at T_0 probably varied similarly with self-assessed health, whether these symptoms were reported or not. If the baseline data are missing conditionally at random, then conditioning on self-assessed health should eliminate the association of missing baseline data with symptoms reported at T_1 (Table 3). Indeed, a loglinear model (14), that includes two-way interactions of self-assessed health with symptoms reported at T_1 and self-assessed health with symptoms missing at T_0, fits the data quite well (likelihood ratio: 6.47, df=6, p=0.37). This is the conditional independence model: given self-assessed health, the number of symptoms reported at T_1 is independent of symptoms missing at T_0. Thus, if the number of symptoms at T_1 accurately predicts the number experienced at T_0, then, given self-assessed health, the number of symptoms experienced at T_0 does not depend on all seven of these questions being answered at that time. The distributions of symptomatology can therefore be weighted by self-assessed health to adjust for the missing data.

DISCUSSION

This paper has utilized the design of a longitudinal study to address two issues concerning the validity of the results obtained by mixed mode surveys. With regard to mode-related response variation, it was found that such variation is probably not caused by the response modes themselves but is probably caused by characteristics of the self-selected respondents to each mode. It is not yet clear what characteristics are involved. Respondents to the initial and followup modes could have different health profiles, which would imply that telephone followup reduced response bias. However, in this survey, mode of response is confounded with wave of response; i.e., early responses were obtained entirely by mail and late responses were obtained entirely by telephone. If data quality varies with wave of response, the baseline response differences could still reflect data quality problems, but problems arising from the respondents themselves, not from the response modes. More work is clearly needed to identify the characteristics of the respondents that generated mode-related response variation. Still, the results are encouraging because they indicate that one source of biased response, limitations of the response modes, does not account for the response differences that are so frequently observed in mixed mode surveys.

With regard to item nonresponse, it was found that the levels of missing health data on mailed questionnaires vary with health status. However, approximately unbiased distributions of health data in the target population can be obtained by weighting the observed data by the distribution of self-assessed health.

Perhaps the most important feature of item nonresponse is that nonrandomly missing data can bias inferences from surveys. This problem is certainly not unique to mixed mode surveys. Nonrandom item nonresponse has been identified even in face-to-face interview surveys (15). Callbacks or record checks may be employed to fill in the missing data but, where this is not feasible, other methods of adjustment must be employed. The strategy explored here, of exploiting items that are highly correlated with the unobserved data and that themselves suffer little item nonresponse, is relatively cheap and easy to implement. It also appears to be a valid approach.

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TABLE 1. Associations of Response Mode at T_0 with the probability that responses changed between T_0 and T_1, given response at T_0, or between T_1 and T_2, given response at T_1.

Comparison	Initial Response	Associations (p<0.05 for each)
T_0 vs T_1	yes	1*
T_0 vs T_1	no	0
T_1 vs T_2	yes	0
T1 vs T2	no	1**

* N= 377, X^2=5.06, df=1, p=0.024
** N=1913, X^2=3.89, df=1, p=0.049

TABLE 2. Counts of Missing Data at T_0, given self-assessed health, standardized by education among subjects who assessed their health as the same as their peers'.

Health-Related Questions

Number Missing	Self-assessed Health Worse	 Same	 Better
0	52.9%	63.5%	68.8%
1-2	21.0	20.1	16.7
3-9	18.6	10.4	9.6
10-69	7.6	6.1	4.9
N	389	2951	2351

Socioeconomic/Behavioral Questions

Number Missing	Self-assessed Health Worse	 Same	 Better
0	83.3%	82.7%	81.8%
1-2	11.5	12.5	12.8
3-18	5.1	4.9	5.3
N	389	2951	2351

Table 3. Physical Symptoms at T_1, given the number missing at T_0.

Symptoms (T_1)	Symptoms Missing (T_0) 0	 ≥1
0	32.6%	24.0%
1-2	47.7	45.0
3-7	19.7	31.0
N	1854	100

TABLE 4. PHYSICAL SYMPTOMS at T_1, given self-assessed health at T_0.

Symptoms (T_1)	Self-assessed Health (T_0) Worse	 Same	 Better
0	8.9%	28.5%	39.3%
1-2	25.3	47.6	49.1
3-7	65.8	23.9	11.6
N	79	951	855

Session T

Health and Its Interaction With Social, Economic, and Demographic Characteristics

DATA FOR AN AGING POPULATION

INTERACTION OF HEALTH AND PENSION: THE EFFECTS ON WOMEN'S EARLY RETIREMENT

Linda Liska Belgrave and Marie R. Haug, Case Western Reserve University

Introduction

Concern over the trend toward early retirement and the possible effect of government policies on this trend suggest that this form of retirement differs from later retirement and is somehow problematic. Although it is not certain that this trend will continue, retirement before 65 is likely to remain an option for older workers and, thus, endure as a labor market influence.

The relative influences of health and pension coverage on the decision to retire before age 65 are unclear. While many factors have been found to influence retirement, these two are often cited as being the most important. Their significance for women is virtually unknown, primarily due to lack of research and reliance on inadequate samples.

In early studies, the use of retrospective survey questions (e.g. "Why did you retire?") led many investigators to the conclusion that health was the most important factor in the decision to retire (1), because poor health made continued employment difficult and pushed people out of the labor force.

Simple eligibility for social security is usually found to be a significant but not dominant predictor of retirement (2,3). Stronger effects of benefits occur where private pensions provide a second source of retirement income (4). Such findings have generally been interpreted as indicating that retirement benefits are an inducement to retire.

The change to a retirement status can thus be motivated by several factors. Health considerations could push individuals out of a work career while the availability of a pension might tend to pull towards retirement. Furthermore, the relationships between these factors are likely to be complex, with financial considerations sometimes overriding the push of poor health and vice versa.

Single women have been found to exhibit variable effects similar to those found important in male retirement (e.g., 5) and the argument of similarity has been extended to all women (6). However, married women, who constitute the larger part of the older female labor force, differ from men and single women in that many have discontinuous work histories, interrupted by one or more breaks usually related to child rearing. Hence, single and married women can be expected to differ in both their dependency on their own earned retirement benefits and the work histories that lead to these benefits.

The effects of retirement are likely to depend upon the outcomes examined; while income and health may change for the worse following retirement (see 7 for contradictory data) subjective well-being is more stable (8). This central finding on attitudinal adaptation to retirement of men has been confirmed in recent research on women's retirement (9).

Studies of women's retirement have had a varied and sometimes contradictory history. Early speculative accounts assumed that women who retired adjusted easily, and did so because women normally experience roles outside of the labor force and lack commitment to work (10). Several more recent studies have attacked these assumptions and some have reported greater adjustment problems among women retirees than among their male counterparts (11,12).

Most investigations of female retirement have used convenience samples or occupational samples of atypical women, so that results cannot appropriately be generalized (11-14). Many do not include men in their samples for comparative evaluation (15). Thus, the need for research on women's retirement continues to be expressed (16,17). This report addressses the following research questions:

1) What are the differences between women and men in the relative importance of health and pension coverage in remaining in the labor force or shifting to a retirement status?

2) Do men and women differ in their adaptation to early retirement? What are the relative influences on these adaptations of objective and subjective evaluations of health and financial situation?

Methods

Data for this report were gathered through face-to-face structured interviews with 521 men and women aged 60-64 during the first survey (fall, 1983) of a longitudinal study of health and women's retirement (a response rate of 66%). The sample was drawn from the membership of a health maintenance organization in a midwestern, industrial SMSA. To insure adequate numbers of women who were or had been employed, only those persons who carried the health plan in their own name were sampled and women were overselected. Given the age range of the sample, the 181 respondents who were retired at the time of the interview had taken early retirement. Due to the source of the sample, persons in the lower economic strata, those who cannot afford private health insurance or do not get it as an employee benefit, are not included.

The measurement of labor force status took into account three items -- self-definition, work history (including current employment status) and receipt of retirement benefits. In most cases these three items were in agreement and self-definition as retired or working was accepted for the final measure. Labor force status was dichotomized as working or retired from primary occupation. Some retirees were working part-time.

Adaptation to retirement was measured with a ten-item semantic differential scale. Respondents were asked to rate their own retirement on a seven-point scale between word pairs such as "peace of mind-worry" and "useful-useless." The resulting scale had a theoretical range of 10 (positive view) to 70 (negative view).

Pension coverage and health status were the independent variables used in the analysis of retirement status. Almost all sample members were, or had been, covered for some retirement benefit (social security, a government or private pension or some combination) on their current or last job. The four percent who had no retirement coverage had to be removed from the sample as too few for meaningful analysis. Pension coverage was dichotomized as social security alone versus pension with or without social security. Three measures of health were employed in this analysis. Self-assessed health over the past year is a subjective, global measure. The two other measures, absence or presence of limiting chronic ailments and the number of work-related activity limitations (e.g. reading, lifting heavy objects and standing for extended periods of time), are more objective and specific.

The analysis of adaptation to retirement used two of these health measures--self assessed health and activity limitations. Financial status was also measured with both a subjective evaluation and a more objective, specific index. The subjective measure combined two items concerning adequacy of current standard of living. This was dichotomized as--has enough money and same or higher standard of living as pre-retirement versus insufficient finances or a post retirement lower living standard. Retirement Benefits, the specific measure, is a simple sum of monthly social security and pension received by the respondent personally. It includes any benefits received by virtue of being covered as a spouse or widow but not those paid directly to the marital partner.

Control variables included in the analyses were average income during the last five years (of employment), type of occupation longest held, attitude toward retirement, marital status, age, race, and years of schooling plus, for adaptation, satisfaction with the last job. The selection of an income measure that was appropriate for both retirees and employed persons was difficult. Current annual income, a commonly used control variable, could not be used because it could have been an influence on the retirement decision for those still working but an outcome of that decision for retirees. Average monthly income over the past five years (last five years of employment for retirees) was used as a rough measure of the economic situation in which the retirement decision was made. This was a self-reported retrospective measure and, as such was subject to unreliability. However, it was more appropriate than the alternatives in terms of time sequence and theory.

Results

Higher proportions of men than women were retired, with white men being the most likely to be retired (52%) and Black women the least (29%). These differences were statistically significant at the .01 level (see Table 1).

The first step in analysis was the examination of bi-variate relationships between labor force status, health and pension availability, calculated separately for women and men. For women none of the independent variables were related to labor force status at a statistically significant level when considered separately. However, an earlier analysis showed that self-assessed health was a predictor of labor force status when women were analyzed separately by race, with the relationships running in opposite directions for Blacks and whites. Black women in bad health were less likely to be retired than those in good health (Cramer's V = .22) while white women with bad health were more likely to be retired (Cramer's V = .21) than healthy white women.

Two of the health variables were statistically significantly related to labor force status for men. Those with more activity limitations (ADL) or with a limiting chronic physical problem were more likely to be retired than were men with no limitations.

The availability of a private or government pension was not related to labor force status for either gender.

Joint effects of all independent and control variables were analyzed using two logistic regression models (18), each of which was examined for the entire sample, for women alone and for men alone. Results of the full model (not presented here due to space limitations) were examined and only those variables that entered at least one of the equations at a statistically significant level or were crucial theoretically were retained for the reduced model. The final results varied substantially between women and men. (Table 2).

For the entire sample pension and activity limitations entered the equation at statistically significant levels, in addition to gender, last income, attitude toward retirement, race and age. Relationships were in the expected directions, with the exception of last income.

When the data for women were examined separately a different picture emerged. Neither activity limitations nor pension coverage was related to labor force status at a statistically significant level. However, self-assessed health was a predictor for women, with women who saw their health as poor more likely to be retired than others. Last income, attitude toward retirement, race and age followed patterns similar to those for the sample as a whole.

For men, on the other hand, while pension coverage remained as a predictor, last working income did not. The effects of health variables were mixed. Self-assessed health and activity limitations were related to early retirement, but in opposite directions. That is, men who had more activity limitations and men who saw their health as good were more likely to be retired than other men. Other relationships were similar to those for women.

Thus, when independents and controls were examined jointly, pension coverage and activity limitations were predictors of early retirement for men only, while last working income mattered only for women. The effects of self-assessed health for men were the opposite of those for women. For both genders, whites, those who viewed retirement favorably and older people were more likely to be retired than were others.

Women and men did not differ in their overall adaptations to early retirement. Both genders described their experiences in positive terms, with mean adaptations scores of 53 and 55, respectively.

As expected, women received smaller retirement benefits than men; women's average monthly benefits were $468 compared to $808 for men, a statistically significant difference. In terms of objective health, the genders were the same, with both men and women experiencing difficulties with two to three activities, on average. Surprisingly, subjective evaluations of finances and health did not follow the same pattern. Although women's retirement benefits were only about 60% of those received by men, they were as likely as men to evaluate their financial situation positively, with slightly over half reporting that they had enough money and had had no decrease in their standard of living since retirement. Both men (71%) and women (65%) evaluated their health positively, as good or excellent.

In the multivariate analysis for women, subjective evaluations of health and finances entered the equation at statistically significant levels (Table 3). (B = .28, -.34 respectively). Women who evaluated their health and finances positively also tended to rate their retirement positively. The introduction of controls added nothing to the explained variance of 17 percent, indicating that these relationships held regardless of race, longest held occupation, marital status and past job satisfaction.

For men, on the other hand, the objective measure of health, work activity limitations, and the subjective measure of finances were predictors of adaptation to retirement, with equal effect (B = .35 and .33). When controls were allowed to enter the equation, only race did so at a statistically significant level. For men, objectively better health, subjective evaluation of finances as adequate and being Black were positively related to high evaluations of retirement with an explained variance of 27 percent.

Discussion

In answer to the first research question, the logit analysis shows pension coverage is a predictor of early retirement for men, but not for women. This may be due to women's lesser likelihood of collecting a pension, even when covered, and their lower average benefits.

Self-assessed health, a subjective measure, predicts early retirement for women, with women who evaluate their health as poor being more likely to be retired than others. For men, limitations on activities has a similar relationship to retirement. However, when this and other variables are controlled, men who evaluate their health as good are more likely to be retired than those who see it as poor. This finding is contrary to theoretical expectations and may reflect an evaluation of health as poor among those who cannot afford to retire and, likewise, good among those for whom retirement is a relief from physically demanding jobs. It is noteworthy that the more objective health measure of activity limitation did not affect women although it was pertinent for men. It appears that women are less likely to respond to limiting physical conditions by retiring than are men.

The finding that whites are more likely to be retired than Blacks probably reflects the relatively advantaged positions of whites in terms of retirement benefits received and financial resources generally.

In response to the second research question, on adaptation, both genders tend to view their experiences in retirement as more positive than negative and both men and women are in equally good health. The only retirement characteristic on which they do differ is financial situation, with women receiving objectively smaller retirement benefits than men, but evaluating their finances similarly to men.

In the multivariate analysis, objective measures of health and finances have only weak non-significant relationships to overall adaptation for women. For men, on the other hand, while effects of retirement benefits are also weak, objective health status (ADL) is a good predictor of adaptation.

Turning to subjective evaluations of retirement standard of living and health, the results for women are what one might expect, suggesting that the impact of health and finances may be indirect, filtered through women's past experiences and expectations. For men, self assessed health is not a significant predictor.

Finally, the finding that Black men tend to view their retirement more positively than white men is unexpected, given that they are likely to be in poorer health and have fewer financial resources. It may be that for Black men retirement is more likely to be a release from adverse working conditions and, thus, more pleasant compared to previous experiences.

This is a cross-sectional analysis and causal relationships could not be tested because of the lack of appropriate time sequencing. Although there are some limits to the generalizability of these results because the sample was drawn from a health maintenance organization, earlier analyses have shown no evidence of bias in demographic characteristics, except that arising from the sampling plan to over select women. It is clear that different motivations toward retirement apply to women as against men and that while men and women adapt to early retirement similarly, they are adapting to different financial situations through different processes.

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TABLE 1 -- LABOR FORCE STATUS BY GENDER AND RACE

	White		Black	
	Women %	Men %	Women %	Men %
Retired	40	52	29	32
N	186	122	89	38

$\chi^2 = 12.25$ d.f. = 3 $p < .01$; Cramer's V = .17

TABLE 2 -- REDUCED MODEL LOGISTIC REGRESSIONS ON LABOR FORCE STATUS OF PENSION, HEALTH, RETIREMENT ATTITUDES AND CONTROL VARIABLES

Variable	Entire Sample b	Women b	Men b
Female	-.45**	---	---
Pension	.26*	.23	.63*
Last Income	-.07**	-.09**	-.05
ADL Work	.05	.01+	.15**+
Self-Assessed Health	.06	.15*	-.21*
Retirement as Freedom	.11	.17*+	-.06+
Retirement as Decline	.26**	.20*	.43**
White	.37**	.28*	.54*
Schooling	-.07	-.07	-.07
Major Occupation	-.02	.08	-.21
Age	.25**	.24**	.29**
Intercept	-20.74**	-21.01**	-22.63**
N	394	253	141

[a] Variable Coding: Reference categories--Labor Force Status (still working), Female (male), Pension (social security only), Chronic Conditions (no limiting chronic conditions), Married (not married), White (Black); Other Variables Meanings of High Scores--Last Income (high income), ADL Work and Self Assessed Health (poor health), Retirement as Freedom and Decline (positive view of retirement), Schooling (few years of school), Major Occupation (lower status occupation), Age (older)

*p < .05 one-tailed t-test
**p < .01 one-tailed t-test

+Difference between coefficients for women and men statistically significant at .05 level.

TABLE 3 -- REGRESSIONS ON ADAPTATION TO RETIREMENT

A. Women (N = 86)

	B	b
Retirement Benefits	.11	.18
Activity Difficulties	.10	.18
Standard of Living	.28***	1.25***
Global Health	-.34***	-.91***
Intercept		5.64

R^2 = 17*** F = 5.48 d.f. = 4,81

B. Men (N = 67)

	B	b
Retirement Benefits	.10	.13
Activity Difficulties	-.35***	-.62***
Standard of Living	.33***	1.40***
Global Health	-.10	-.26
Race	-.27***	-1.43***
Intercept		6.67

R^2 = .27*** F = 5.88 d.f. = 5,61

*p $<$ .10
**p $<$ .05
***p $<$ .01

[a] Controls (reference categories) available for entry: Race (Black), Longest Held Occupation, Marital Status (non-married), Job Satisfaction

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SOCIOECONOMIC DIFFERENTIALS IN MORTALITY: THE ROLE OF PSYCHOSOCIAL FACTORS *

David R. Williams, Yale University

Some of the earliest mortality records indicate the existence of a strong inverse association between socioeconomic status (SES) and mortality (1). Persons of high social status lived longer than their less favoured counterparts. More recent studies reveal that socioeconomic disparities in mortality have not changed over time (2,3). At the same time, researchers are still largely unaware of the causal dynamics that influence the SES gradient in mortality. Explanations of SES-mortality differentials have traditionally focused on the pathogenic living conditions of the poor such as poor sanitation and overcrowding, the tendency of severely ill people to drift downward in social status, and inadequate access to and/or utilization of medical care by the poor. However, it is becoming increasingly evident that these explanations alone have limited power to explain the persisting association between social stratification and health status (4). Most impressive is the growing evidence that suggests that differences in medical care resources cannot account for SES differentials in health status (4-6).

There is a growing convergence among researchers that a substantial part of the SES differential in health status is linked to "general features of lower class living environments that compromise bodily defense" (4, p.6). This approach affirms that SES indicators are crude ways of describing the conditions of life of groups located at different positions in the structure of society.

Psychosocial factors, such as supportive social relationships and preventive health habits, have been nominated as potential linkages between social stratification and health status (7,8). Striking evidence from numerous studies indicate that social integration, social networks, and social support are all predictive of lower morbidity and mortality (9,10). A more extensive literature on marital status has also consistently found that the married enjoy better health than the unmarried (11). Similarly, several researchers have reported that preventive health practices (such as not smoking, drinking moderately if at all, and maintaining normal weight) are predictive of lower mortality and morbidity (9,12).

The available evidence also indicates that these protective health factors are positively related to SES. Dohrenwend and Dohrenwend (13) note that the divorce rate is inversely related to SES, and that even when marriage is not broken, spouses in the lower social strata are not emotionally supportive of each other. Likewise, Belle (14) indicates that one-half of all families living in poverty do not include a husband-father, lower SES persons are less likely to be happily married, and lower SES women are less likely to turn to their husbands as confidants. With regard to health practices, the Alameda County study found that persons in the lower SES groups were three to four times less likely than those of higher social status to report health enhancing habits (9). National data also reveal a strong positive relationship between SES and preventive health behaviors.

Although it has been frequently noted that psychosocial factors may play a major role in accounting for the association between SES and mortality, this possibility has rarely been subjected to empirical verification. Accordingly, this paper reports analyses from the Tecumseh Michigan Community Health Study that systematically explore the extent to which two psychosocial resources -- health practices and social integration -- are linked to SES and can explain the SES gradient in mortality.

METHODS

Study population. The present analyses are based on adults aged 20 or older who were interviewed and medically examined in the three major waves of data collection in the Tecumseh Community Health Study (15). The population of adults is 4,687, 4,848, and 4,481 for the three interview cycles in 1959-1960, 1962-1965 and 1967-1969, respectively. The participation rates for the three series of interviews are 88, 82 and 71 percent, respectively. Complete mortality ascertainment for all participants, whether living in the study area or not, was established between 1978 and 1979. Death certificates were obtained for almost all reported deaths.

Measures. Mortality from all causes is the central dependent variable in all analyses. Formal education measured in years of schooling is the primary indicator of socioeconomic status. Preliminary analyses revealed that there were no meaningful differentials in mortality for those who had received zero to 11 years of schooling. Accordingly, zero to 11 years is utilized as the lowest social status group in all the analyses. At Wave one forty-three percent of the population falls into this category. The other education categories employed are 12 years, 13-15 years and 16 or more years. Although the central focus is on education, differentials in health status by total family income, in dollars, and occupation defined as broad occupational groupings will also be examined when those measures are available in the Tecumseh data. Occupational information for all respondents is available only at Round One, while income data was collected only at Rounds Two and Three. It is hypothesized that the education effect will be larger than, and independent of SES differentials for occupation and income.

Three indicators of health practices are utilized. These are obesity, smoking, and alcohol consumption. Information on alcohol use was obtained only at Round One and Round Three. A relative weight index was calculated using weight divided by the square of height and multiplied by a constant based on median weights from the Metropolitan Life Insurance Company Tables (16). In all analyses, relative weights were divided into three categories: a) underweight, less than 90 percent of desirable weight, b) normal weight, 90 to 120 percent of ideal weight, and c) obese, greater than 120 percent of desirable weight for height.

Four ounces of ethanol per week was used as the cut-point to distinguish light from heavy alcohol use. This decision was based on the pattern of alcohol consumption in Tecumseh in 1959-1960. Preliminary analyses revealed that only 20 percent of the individuals who consumed alcohol used more than four ounces of ethanol per week.

Household size (that is, a count of persons in one's household), and marital status are the measures of social integration employed. Both of these were used by Durkheim (17) in his seminal work on social integration and it was his contention that household size is more consequential than marriage (17, p.198). Consistent with Durkheim's initial theorizing, one recent study found household size to be more strongly related to mortality risk than marriage (18).

Potential confounding variables utilized in the analyses are age in years and the following indicators of initial health status: 1) serum cholesterol; 2) blood glucose; 3) FEV_1 score, forced expiratory volume in one second; 4) a diagnosis of suspect or probable coronary heart disease; 5) chronic bronchitis; and 6) hypertension.

Statistical analysis. Simple descriptive analyses are used to present SES differences in exposure to psychosocial resources. However, this report relies primarily on the multiple logistic function analyses using maximum likelihood-estimation procedures (19), for estimating the magnitude and statistical significance of the relationships among SES, psychosocial factors and mortality. To facilitate interpretation approximate relative risk ratios are presented. The relative risk is the ratio of the expected mortality rates for persons at the highest and lowest levels of SES.

RESULTS

Socioeconomic Differentials in Mortality

Inspection of the zero-order relationship between mortality and educational attainment in Tecumseh indicates that there is a clear inverse relationship between mortality and education for both males and females at Wave One. The excess mortality of the lowest education group is also clearly evident at Wave Two and Wave Three. Men with less than 12 years of education are twice as likely to die in the follow-up period when compared to college graduates. The association is almost as strong for females.

Preliminary age-adjusted multivariate analyses were performed to assess the relative strength of education, income, and occupation as predictors of mortality. Mortality among males is consistently highest at the two lowest education levels. The coefficients for education are reduced slightly but remain significant when adjusted for income or occupation. However, there are no occupational or income effects for males independent of education. For females, the lowest mortality is consistently found at the second highest education level. At the same time, when occupational data are available, professional and managerial female workers have significantly lower mortality than all other occupational groups. The size and statistical significance of the coefficients for occupation are reduced, but only slightly, when controlled for education. There is no clear and consistent relationship between income and mortality for females. In sum, consistent with earlier research, education is the best prediction of health status (2).

Psychosocial Factors and Education

The association between health practices and social status at Waves One and Three are presented in Table 1. Obesity is unrelated to educational status for males in Tecumseh. In contrast, there is the expected inverse relationship between years of schooling and obesity among women at Wave One. And although the percentage differences are not large, the Wave Three data reveal that there is a trend towards increasing obesity among Tecumseh females and a widening of the SES differential.

At Wave One, men with a high school education or less are more likely to smoke and smoke more heavily than their more educated peers. By Wave Three, fewer males smoke in Tecumseh, but the association between smoking and education has not changed. On the other hand, Table 1 shows that there is a positive association between smoking and education for women at Wave One. Female college graduates exhibit the highest rate of smoking. The Wave Three data reveals that there has been a slight reduction in smoking for all of the SES groups. However, the reduction is greatest for the well educated females, such that smoking is now unrelated to educational attainment for Tecumseh women. With regard to alcohol use, Table 1 indicates that the heavy consumption of alcohol is positively associated with social status, for both sexes, at both of the data collection periods under consideration.

Analyses of the association between social integration and educational status revealed that there is a strikingly high level of social integration in Tecumseh with very little SES variation. At all educational levels, for both sexes, 80 percent or more of Tecumseh residents are married. Similarly, while there is a slight tendency for males and females with the least education to live in one or two person households, there is no convincingly large SES pattern for household size. The Wave Two and Three data indicate that there was no major shift over time either in the association between education and social integration or in the overall level of social integration in Tecumseh.

Table 1
Distribution of health practices by education,
Tecumseh Community Health Study, 1959-1969

MALES

Education in Years	Obesity				Smoking				Heavy Drinking			
	Wave 1		Wave 3		Wave 1		Wave 3		Wave 1		Wave 3	
	%	N	%	N	%	N	%	N	%	N	%	N
0-11	38	(973)	41	(718)	62	(1,002)	50	(723)	18	(954)	17	(737)
12	35	(740)	43	(824)	64	(767)	50	(832)	20	(743)	26	(845)
13-15	32	(202)	40	(253)	56	(208)	43	(254)	20	(200)	19	(257)
16+	35	(189)	39	(203)	46	(195)	34	(205)	33	(188)	31	(207)
N		2,104		1,998		2,172		2,014		2,085		2,046

FEMALES

Education in Years	Obesity				Smoking				Heavy Drinking			
	Wave 1		Wave 3		Wave 1		Wave 3		Wave 1		Wave 3	
	%	N	%	N	%	N	%	N	%	N	%	N
0-11	52	(915)	56	(721)	34	(946)	31	(724)	3	(906)	4	(730)
12	40	(1,045)	42	(1,161)	34	(1,067)	31	(1,178)	5	(1,035)	6	(1,190)
13-15	38	(220)	40	(264)	36	(233)	32	(267)	8	(218)	9	(269)
16+	36	(140)	33	(156)	44	(142)	35	(161)	12	(135)	15	(162)
N		2,329		2,302		2,388		2,330		2,294		2,351

Health Practices and Mortality Differentials

In the follow-up period from Wave One both smoking and heavy alcohol use are predictive of increased mortality risk but only among males. Table 2 shows the relationship between SES and mortality and how it is affected by health practices. Three models are presented for males and females, for each of the data collection points. The first column presents the age-adjusted logistic coefficients for educational differentials in mortality. The second column shows how these coefficients are altered when adjusted for the health practices. Health practices were entered singly and in combination but only the final model in which all health practices are entered simultaneously is presented. The primary interest here is in assessing change in the logistic coefficients for SES between model one and model two. If exposure to psychosocial factors is partly responsible for the SES differentials in mortality, there should be reductions in the size of the coefficients for SES from the first to the second model. In the third column, the association between education and mortality is further adjusted for initial health status. This final model includes all the covariates of the previous models.

For males at Round One, the inverse association between education and mortality is only marginally significant. The coefficients for education become somewhat larger when health practices are considered but they are reduced to the approximate size of the original relationship when controlled for the biomedical variables. Analyses not shown reveal that while smoking slightly reduced the mortality differentials, adjustment for weight status and alcohol use tends to increase them. Among females, health practices are unrelated to mortality risk and women with some college education have lower mortality than the other education groups. This association is only barely reduced when health practices are introduced and becomes slightly stronger in the final model that includes the biomedical controls. In sum, at Wave One, there is no striking pattern of SES differentials in mortality, for either sex, and health practices are of little consequence in explaining the existing mortality differentials.

At Wave Two, health practices are related to the mortality status of males only. Heavy smoking is again predictive of increased mortality risk for men and both obese and normal weight males tend to have lower mortality risk than their underweight counterparts. There are no social status differences in mortality and no relationship between health practices and mortality for females. SES differentials exist only for males and the coefficients for education are larger than those at Wave One. The two lower education groups have elevated mortality risk when compared to their more educated peers. In fact, the relative predicted risk of dying during the follow-up period of a person with less than 12 years of education compared to a college graduate is greater than two. When health practices are added to the model, the coefficients for education are reduced but not markedly. The relative risk

Table 2
Multiple logistic coefficients for association of education with mortality, Tecumseh Community Health Study, 1959-1979++

	MALES			FEMALES		
	Adjusted For			Ajusted For		
Education in Years	Age	Health Practices	Other Risk Factors	Age	Health Practices	Other Risk Factors
WAVE ONE						
0-11	.429+	.465*	.418+	.270	.293	.200
12	.392+	.428+	.399	.305	.361	.333
13-15	.088	.182	.127	-.787*	-.758*	-.851*
16+(omitted)						
Rel. Risk[1]	1.535	1.592	1.519	1 .310	1.340	1.220
WAVE TWO						
0-11	.773**	.710**	.667+	.180	.250	.184
12	.693+	.660+	.676+	.286	.357	.329
13-15	.078	.002	.105	-.457	-.425	-.420
16+(omitted)						
Rel. Risk[1]	2.166	2.034	1.947	1.197	1.284	1.201
WAVE THREE						
0-11	.699*	.535+	.455	.053	.076	-.051
12	.701*	.595+	.534+	.547	.575	.530
13-15	.371	.275	.270	-.361	-.364	-.398
16+(omitted)						
Rel. Risk[1]	1.952	1.707	1.575	1.054	1.079	.951

+ = $p \leq .10$; * = $p \leq .05$; ** = $p \leq .01$ (two-tailed tests)

++ After deletion of missing data, the numbers are 2122, 2012 and 1707 for males and 2259, 2171 and 1927 for females, Waves One, Two and Three, respectively. Risk factors controlled were cholesterol, blood glucose, FEV$_1$, coronary heart disease, bronchitis and hypertension.

[1] Relative predicted risk of dying during the follow-up period of a person with less than 12 years of education compared to a college graduate, assuming mean scores on all control variables.

changes from 2.17 to 2.03.

At Wave Three, for the first time, smoking is predictive of increased mortality risk for both males and females. Among males only, obese and normal weight individuals again have a lower mortality risk than the underweight. Once again SES differentials in mortality exist only for males. The two lower education groups have higher mortality risk than the two higher social status groups. At Wave Three, however, the introduction of health practices produces the largest reductions in the coefficients for education that has been seen so far. The relative risk is reduced from 1.95 to 1.71.

Do age differences exist in the potential for health practices to explain SES differences in mortality? The relationship among health practices, SES and mortality was examined for three age groups: 20-39, 40-59 and over 60 years. Overall the pattern of results is similar for the three age groups, although, consistent with earlier research, there is a tendency for the association between health practices and mortality to be largest for the 40-59 age group.

In sum, socioeconomic differentials in mortality were not large at Wave One and health practices played no role in accounting for the relationship. However, when a clear pattern of SES differentials emerge for males at Waves Two and Three, health practices play an increasingly important role in explaining the association between social status and mortality. Cigarette smoking is consistently related to increased mortality risk, for males, while the effects for weight status and alcohol use are fewer and weaker. While it has been consistently reported that education predicts the health status of women better than income (2,7), there was no clear and consistent association between mortality and either income or education for Tecumseh women. Moreover, except for cigarette smoking at Wave Three, health practices were unrelated to the mortality risk of females.

Social Integration and Mortality Differentials

Marriage was inversely related to mortality and, consistent with the literature, the relationship was stronger for men than for women. However, there was no association between household size and mortality. Failure in replicating the findings of Welin et al. (18) could well be due to differences in the structure and patterns of social life between Gothenburg, Sweden and Tecumseh, Michigan. It was noted earlier that, in Tecumseh, social integration is unrelated to SES and the overall level is high. Not surprisingly then, social integration plays no role in accounting for the association between educational status and mortality.

DISCUSSION

This paper systematically explored the extent to which psychosocial factors could account for SES differences in mortality. Where a clear SES gradient exists, health practices (primarily smoking) play a moderate role in accounting for the relationship. The importance of health practices in explaining SES differences in mortality was greater at Waves Two and Three than at Wave One, suggesting that the basis for the SES differential in mortality is changing. This pattern of results may indicate that as adequate nutrition and housing, improved sanitation, mass immunizations and access to medical care become universal in a given community or society, psychosocial factors, like those considered here will become increasingly important determinants of health status. Although the psychosocial factors under consideration were significant predictors of mortality, they did not play a larger role in explaining mortality differences most probably because they were not as systematically linked to SES in Tecumseh as the literature predicted. The association between health practices and SES was complex, sex-specific, and weaker than expected. The weak relationship between health practices and SES was especially surprising in the case of cigarette smoking. National data indicates, for example, that high school graduates are fifty percent more likely than college graduates to smoke cigarettes (20). Failure to find a stronger association between health practices and health may well be due to the sociodemographic characteristics of Tecumseh. Tecumseh has an unusually high SES profile, good medical care and lacks representation of the rural poor, urban poor and minority poor that constitute a non-trivial part of the lower social strata in the U.S. (21).

The community of Tecumseh did not conform to our predictions with regard to the association between SES and social integration. The overall level of social integration was high and unrelated to SES. This clearly highlights the important sociological fact that social integration is a characteristic not only of individuals but also of groups. Thus, just as individuals can be ranked according to their level of social integration, communities can be similarly described. Further, the identification of the determinants of social integration and support at the societal level has important implications for the implementation of effective interventions (22). There are some suggestions in the present data. Levels of social integration were found to be high in Tecumseh. Tecumseh is an industrial town, nestled in a rural agricultural environment, that boasts a low rate of unemployment, and higher than average levels of education and income. Nonetheless, these speculations need to be submitted to empirical verification.

The analyses reported here rather than being definitive, are merely illustrative of what can be a fruitful approach to understanding the persisting association between social stratification and health. This approach is premised on the assumption that social structures shape individual values and behavior and that SES differences in health status are due, at least in part, to conditions of life that derive from an individual's structural position. The present analyses focused on health practices and social integration. A broader range of health behaviors are probably related to health status than those used here (9). Other relevant health practices include nutritional behavior, seat belt use, breast self-examination and drug use. With regard to social relationships, additional research is needed to identify which components of social support, social integration and social networks are consequential for health and to isolate the conditions under which different aspects of relationships can be expected to have particular effects (23).

The two psychosocial factors considered here are only two of the possible pathways through which social stratification can affect health status. The identification and modification of other pathogenic factors is an important area for future research. Other promising possibilities include stress and attitudinal orientations such as beliefs about personal control over one's environment. Both of these factors are predictive of health status and clearly linked to SES (24-27). In short, there is clearly a need to consider, in a more integrated way than this study or others have done previously, how a number of social and psychological resources vary by SES and combine to affect health status in the middle and later years of life. The significance of this research agenda must be assessed against the background of the extremely fragmentary evidence that is currently available about the causal dynamics that influence the SES gradient in health status.

Research efforts of this kind, in addition to advancing our theoretical understanding of the relationship between social stratification and health outcomes, can also inform policy initiatives to achieve greater equality in society. The evidence linking psychosocial factors to health status has sometimes been used to "blame the victims" for their failure to follow healthier lifestyles. Some have called for national educational initiatives targeted at the poor, to persuade them to abandon their high-risk lifestyles. On the other hand, if health enhancing psychosocial factors derive from socioeconomic position, then the elimination of unhealthy lifestyles, and the consequent improvement of health status may be contingent on programs designed not to change attitudes and behavior but to improve the SES conditions of the lower social status groups.

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THE INFLUENCE OF ECONOMIC AND DEMOGRAPHIC FACTORS ON CAUSE SPECIFIC MORTALITY IN AN ELDERLY POPULATION AGED 65 TO 74

Diane Dewar Dunz, John J. Tarmey and Patrick J. Roohan
New York State Department of Health, Albany, N.Y.

The accelerated decline in total mortality is resulting in an increasing number and age distribution of the elderly population. Due to the aging baby-boom generation, this subgroup will have changed sufficiently by the turn of the century to warrant a closer investigation of the health, social, and economic consequences of aging (1).

Several studies have investigated the impact of demographic and economic status on mortality. There has been an agreement among most researchers that, in general, individuals in lower socioeconomic strata are more likely to have poorer health outcomes and higher mortality rates.

Mechanic (2) concluded that, among other social factors, poverty, education, marital status and employment availability significantly affected health status and mortality. While poverty had frequently been associated with adverse health outcomes, higher educational attainment was related to lower morbidity and mortality. In addition, marital status, an indicator of social integration, appeared to be an important factor in health maintainence. Slater and colleagues (3) investigated the impact of socioeconomic status and personal health practices on health status. They found that perceived health status was associated with socioeconomic status, whether the indicator was education, occupation or family income. Davis and associates (4) discussed the hypothesis that a circular relationship exists between health status and income level. Lower income may adversely affect health while poor health may be a factor in decreased earning capability. These studies imply that health care should extend beyond the physiological problems to the behavioral and social aspects of the individual.

One of the major impediments to understanding the determinants of health status and mortality is the observed differences among segments of the population. This study will attempt to quantify the impact that various demographic and socioeconomic characteristics have on mortality due to malignant neoplasms or diseases of the circulatory system among individuals aged 65 to 74. Socioeconomic subgroups that have a higher chance of mortality due to these two common causes are identified among past labor force participants and among women who have never worked outside of the home.

DATA AND METHODOLOGY.

Certificates of death recorded from 1980 through 1985 with the New York State Department of Health are used as a data source in analyzing the determinants of cause specific mortality using selected characteristics of elderly individuals. The study is separated into two parts, one section overviewing deaths caused by diseases of the circulatory system (ICD codes 390-459) or malignant neoplasms (ICD codes 140-208) versus all other causes of death for past labor force participants, and the other investigating these causes of death for women who never worked outside of the home (ie. women in the home). The latter subpopulation is studied separately due to the lack of occupational and industrial identifiers for this group. All deaths considered are recorded in upstate New York (New York State exclusive of New York City) to upstate residents aged 65 to 74 years.

In this study, deaths for individuals residing in low socioeconomic areas are compared to those residing in the remainder of upstate. Areas are classified according to a composite socioeconomic residence score developed by the Bureau of Biostatistics of the New York State Department of Health and based upon information from the 1980 United States Census. Details of the residence scoring method are in Table I. Scores are assigned to minor civil divisions within the entire upstate region, and to census tracts within thirteen selected counties for which vital statistics information is available according to census tract. These thirteen counties are all relatively urban and part of a Standard Metropolitan Statistical Area. Low socioeconomic areas are defined as having scores no greater than three with median family income less than $15,500.

Data for usual occupation and industry are obtained through a cooperative agreement between the New York State Department of Health and the National Institute for Occupational Safety and Health which establishes an occupational health surveillance system based upon vital records. The main activity of this agreement is the coding of these data as entered on the death certificates. All events to persons between eighteen and seventy-four years are being coded according to the three digit classification system developed by the Census Bureau for use with the 1980 Census.

Occupation codes are categorized according to the coding scheme adapted by Therriault and Logrillo (5) from the original 1970 Census coding system developed by Nam and coworkers (6). These categories are a hierarchy derived from the occupational status scores, which are based on the combined median levels of education and income for incumbents of the occupations considered. The lowest occupational class, class one, is assigned to service workers, farm occupations, handlers, equipment cleaners, and helpers and laborers. The second class includes transportation and material moving occupations, machine operators, assemblers and inspectors, and farm operators and managers. Category three consists of sales and administrative support occupations, clerical, precision production, and craft and repair workers. The highest grouping, class four, is comprised of executive, administrative and managerial positions, professional specialty occupations, and technicians and related support workers.

Industry codes are classified in a standard manner (7). Unlike the occupation codes, industry codes are categorized according to the type of goods or services produced, not the complexity of the production process. The first category includes the agriculture, forestry, and fishing industries. The second group consists of the goods-producing industries such as manufacturing, mining, construction, communication, and public utilities. The third is comprised of the nongovernment service industries of trade, personal, professional and business services, entertainment, finance, and real estate. The fourth class includes federal, state and local government workers.

The distribution of the study population is shown in Table II. In addition to the socioeconomic, occupation and industrial indicators, cause of death is regressed on the following variables: 1. race--two levels: nonhispanic black and nonhispanic white; 2. marital status--four levels: divorced, unwed, widowed, and wed/separated; 3. education--two levels: 0-11 and 12 plus years completed; 4. sex--male and female. Observations with invalid data on any of the relevant variables are excluded from the study. This results in a study population of 112,994 cases.

Logistic regression models are fit to both data sets (8). Each model attempts to predict the probability of death caused by malignant neoplasms or circulatory disease relative to the probability of death due to all other causes. The model is fitted to both samples using the SAS software package to identify the significant factors and interactions that determine mortality caused by malignant neoplasms or circulatory disease (9).

RESULTS.

Logistic regression models are fit using all second order, first order, and main effects, and then reduced according to statistical significance. From this model, odds ratios can be computed for circulatory disease versus all other causes of death, malignant neoplasms compared to other causes of death, as well as the odds ratio of circulatory disease compared to malignant neoplasms. This last ratio is the focus of this paper.

Labor Force Participant Model.

Through preliminary analysis, it was found that occupation class and industry class provided very similar information and inclusion of both increased the complexity of the labor force participant model by a power of four. Industry class was then eliminated because occupation class provided higher association with cause of death. The significant factors included in the reduced form of the model in order of significance are:

1. marital status
2. sex by marital status interaction
3. occupation class
4. sex by occupation class interaction
5. sex by education interaction
6. race by socioeconomic status interaction
7. race by sex interaction
8. race by marital status interaction
9. sex by socioeconomic status interaction
10. education
11. sex
12. race
13. socioeconomic status.

The odds ratios for the parameter estimates of the reduced model are in Table III, with statistical significance at the 0.05 level denoted by an asterisk (*). The average relative risk of death caused by circulatory disease versus malignant neoplasms is the intercept value of 1.771. For this model it can be interpreted that circulatory disease is seventy-seven percent more likely than malignant neoplasms to be the cause of death. The values for the remaining factors are essentially relative risks deviating from this baseline level.

Significant odds ratios from the three most important factors may also be considered from the table. Unweds and those in the two lower occupation classes appear to be at a higher relative risk of circulatory disease compared to malignant neoplasms. For women, those who are black, have less than 12 years of education completed, reside in low socioeconomic areas and are employed in the two lower occupational classes have an increased relative risk of mortality due to circulatory disease. Higher risk groups for men are whites, unweds, those employed in the two upper occupational classes, residents of more affluent socioeconomic areas, and those that have at least 12 years of education. Racial subgroups with a higher chance of death from circulatory disease are blacks who are unwed or reside in remaining socioeconomic areas, and whites who are wed or separated or reside in low socioeconomic areas.

Plots of the significant interactions included in this model can also be constructed. These plots provide a simple way of summarizing the mean levels of each factor within an interaction and confirm the significant cross effects found in the estimated model. For a nonsignificant interaction the lines should be parallel in nature. The interaction plots contain both circulatory disease and malignant neoplasms, and portray reverse image effects on each other due to the constraint that the total sum of all deaths must equal the sum of the three classes of death.

The sex by marital status interaction in Figure 1 displays lines that are not parallel, and also shows an increased risk of circulatory disease for unwed males and an increased risk of malignant neoplasms for married/separated females. Other interactions in the model can also be shown graphically. (These are available upon request.)

Women in the Home Model.

Race, marital status, socioeconomic status and education were used to determine the cause of death for the women in the home subpopulation. The factors that significantly influenced cause of death for this model are:

1. education
2. race by marital status interaction
3. race
4. marital status.

Socioeconomic status has been omitted because it did not have a significant impact on the dependent variable.

Odds ratios for the parameter estimates of the model are in Table IV, with statistically significant ratios at the 0.05 level denoted by an asterisk (*). The average relative risk of mortality due to circulatory disease versus malignant neoplasms for this subpopulation is 1.667. This value is similar in magnitude to the labor force participants and can be interpreted that circulatory disease is sixty-seven percent more likely than malignant neoplasms to be the cause of death. Considering particular factors, it is seen that women with less than 12 years of education completed, wed/separated blacks and unwed whites are at higher relative risk of death from circulatory disease.

The plot of the interaction between race and marital status can be created to display the significant cross effect found in the estimated model. (This is available upon request.)

DISCUSSION.

In summarizing the results of the estimated models for both data sets, several points can be highlighted.

First, educational attainment and marital status are isolated as significant predictors in both data sets. Through education, this study suggests the influence of socioeconomic status on cause specific mortality, where individuals with lower educational attainment have relatively higher risk of death due to circulatory disease. This correlation is consistent with other research concerning the impact of education on health status (10). In this case, the association may not be a result of access to better medical care for particular diseases, but due to a more forward attitude with respect to diet and exercise among those with more education. Marital status is regarded as an indicator of social integration, and it can be inferred that an individual's health status is related to his or her marital decision (11).

Second, occupation classification and the demographic variables of race and sex are also influential determinants of mortality in the labor force participant model. This influence of race and sex on mortality has also been found in other studies based on broader age groups (12,13,14). Contrasting past occupational strata yields a direct comparison of achieved socioeconomic class and lends further credence to the role of the economic condition on cause specific mortality, which has been seen in health research based upon younger workers (15).

It is clear that the occupational and educational subgroups cited may not indicate individuals with poor access to medical care for circulatory disease compared to other diseases. Instead, they may reflect differences in the economic opportunities available among the races and sexes which in turn affect health status. This apparent self-selection into particular mortality outcomes raises questions about aspects of the environment which appear to place lower socioeconomic males, females and minorities at higher risk of specific causes of death. The racial and marital status factors noted may yield further evidence of the influence of social vulnerability on resulting mortality.

Third, the coefficient of the socioeconomic residence score is only significant through its interaction with other variables in the labor force model, and is not included in the reduced form of the women's model. Although this variable is an important indicator of an individual's social class, the lower impact of this variable on cause specific mortality may be due to the timeliness of the data used in the scoring method. Until more recent data is available, 1980 Census data is being used to characterize socioeconomic status for current deaths. Another consideration is that this score is assigned to every individual living in a given census tract or minor civil division, where homogeneity is assumed across each area. This may be a valid assumption on the census tract level, since they are designed to be relatively homogeneous with respect to economic status, population characteristics and living conditions. On the minor civil division level, this assumption may be less realistic.

In general, most of the socioeconomic variables considered have a significant impact on cause specific mortality, either as main effects or interacting with other variables. The relative risk of mortality for these two common causes is not simply influenced by race and sex differences, but by the more subtle differences in education, marital status, occupation and socioeconomic status within these race and sex subpopulations.

The current analysis reaffirms that efforts to improve mortality rates among the elderly need to be focused on the economic and social difficulties associated with lower socioeconomic segments of this population. Women must be focused on in particular since most are relatively disadvantaged. Further incentives must be developed to encourage these groups to engage in preventive health care in order to postpone the onset of debilitating chronic illness.

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Due to space considerations, selected figures and tabulations could not be presented. These are available upon request.

ADDRESS: Diane Dewar Dunz
New York State Department of Health
Bureau of Biostatistics, Room 308
Empire State Plaza Tower
Albany, New York 12237

Figure 1
Interaction Plot of Sex and Marital Status

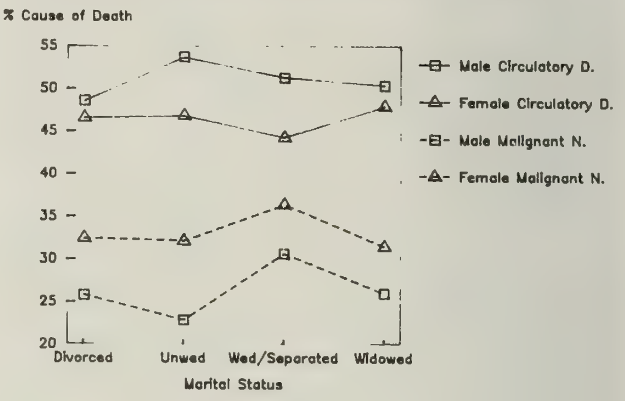


TABLE I: SOCIOECONOMIC SCORING METHOD FOR RESIDENCE AREAS

AREA SUBSCORE	MEDIAN FAMILY INCOME (MI)	% WITH 4+ YEARS OF COLLEGE (PC)	% OF UNSKILLED WORKERS (PU)
0	< $15,500	< 7.0	35.0 +
1	$15,500-17,499	7.0-9.9	26.5-34.9
2	$17,500-19,499	10.0-13.9	21.5-26.4
3	$19,500-23,999	14.0-21.4	16.5-21.4
4	$24,000 +	21.5 +	< 16.5

AREA SES SCORE = (MI SCORE) + (PC SCORE) + (PU SCORE)

TABLE II: DISTRIBUTION OF ELDERLY POPULATION 1980-1985

VARIABLE	LEVEL	LABOR FORCE PARTICIPANT MODEL		WOMEN IN THE HOME MODEL	
		NUMBER	PERCENT	NUMBER	PERCENT
TOTAL		89310	100.0	23684	100.0
CAUSE OF DEATH	CIRCULATORY D.	44519	49.9	11549	48.8
	MALIGNANT NEOP.	27006	30.2	7138	30.1
	OTHER CAUSES	17785	19.9	4977	21.1
RACE	BLACK	3413	3.8	891	3.8
	WHITE	85897	96.2	22793	96.2
SEX	FEMALE	24274	27.2	23684	100.0
	MALE	65036	72.8	0	0.0
MARITAL STATUS	DIVORCED	4335	4.9	547	2.3
	UNWED	8206	9.2	379	1.6
	WED/SEPERATED	56517	63.3	11238	47.4
	WIDOWED	20252	20.7	11520	48.6
SOCIOECONOMIC STATUS*	LOW	7950	8.9	2191	9.3
	OTHER	81360	91.1	21493	90.7
EDUCATION	UNDER 12 YEARS	32192	36.0	9478	40.0
	12 YEARS AND UP	51118	64.0	14206	60.0
OCCUPATION	I	17364	19.4		
	II	18291	20.5		
	III	34960	39.1		
	IV	18695	20.9		
INDUSTRY	1	2688	3.0		
	2	44071	49.4		
	3	37796	42.3		
	4	4755	5.3		

*FOR SOCIOECONOMIC STATUS: LOW CORRESPONDS TO LOW SOCIOECONOMIC RESIDENT SCORE
OTHER CORRESPONDS TO REMAINING SOCIOECONOMIC RESIDENT SCORE

TABLE III: ODDS RATIOS FOR ELDERLY POPULATION LABOR PARTICIPANT MODEL 1980-1985

FACTOR	LEVEL	ODDS RATIO**	
INTERCEPT		1.77	*
RACE	BLACK	.98	
	WHITE	1.02	
SEX	FEMALE	.96	
	MALE	1.04	
RACE*SEX	BLACK FEMALE	1.08	*
	BLACK MALE	.93	*
	WHITE FEMALE	.93	*
	WHITE MALE	1.08	*
MARITAL STATUS	DIVORCED	.95	
	UNWED	1.26	*
	WED/SEPARATED	.78	*
	WIDOWED	1.07	
RACE*MARITAL STATUS	BLACK DIVORCED	.96	
	BLACK UNWED	1.12	*
	BLACK WED/SEPARATED	.90	*
	BLACK WIDOWED	1.00	
	WHITE DIVORCED	1.05	
	WHITE UNWED	.90	*
	WHITE WED/SEPARATED	1.11	*
	WHITE WIDOWED	1.00	
SOCIOECONOMIC STATUS (SES)	LOW	1.01	
	OTHER	1.00	
RACE*SES	BLACK LOW	.93	*
	BLACK OTHER	1.08	*
	WHITE LOW	1.08	*
	WHITE OTHER	.93	*
SEX*MARITAL STATUS	FEMALE DIVORCED	1.02	
	FEMALE UNWED	.94	*
	FEMALE WED/SEPARATED	1.01	
	FEMALE WIDOWED	.95	
	MALE DIVORCED	.98	
	MALE UNWED	1.06	*
	MALE WED/SEPARATED	.99	
	MALE WIDOWED	1.05	
SEX*SES	FEMALE LOW	1.04	*
	FEMALE OTHER	.96	*
	MALE LOW	.96	*
	MALE OTHER	1.04	*
OCCUPATION	I	1.05	*
	II	1.08	*
	III	.94	*
	IV	.93	*
SEX*OCCUPATION	FEMALE I	1.07	*
	FEMALE II	1.05	*
	FEMALE III	.96	*
	FEMALE IV	.93	*
	MALE I	.93	*
	MALE II	.96	*
	MALE III	1.04	*
	MALE IV	1.08	*
EDUCATION	UNDER 12 YEARS	1.03	*
	12 YEARS AND UP	.98	*
SEX*EDUCATION	FEMALE UNDER 12 YEARS	1.03	*
	FEMALE 12 YEARS AND UP	.97	*
	MALE UNDER 12 YEARS	.97	*
	MALE 12 YEARS AND UP	1.03	*

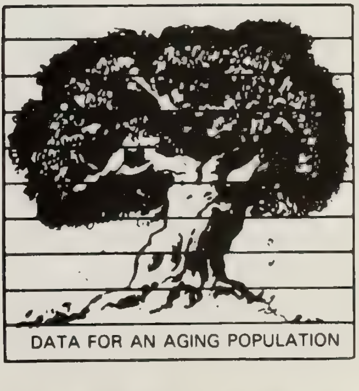
** ODDS RATIO FOR CIRCULATORY DISEASE VS. MALIGNANT NEOPLASMS

TABLE IV: ODDS RATIOS FOR ELDERLY POPULATION WOMEN IN THE HOME MODEL 1980-1985

FACTOR	LEVEL	ODDS RATIO**	
INTERCEPT		1.67	*
RACE	BLACK	.94	
	WHITE	1.06	
MARITAL STATUS	DIVORCED	1.00	
	UNWED	.81	
	WED/SEPARATED	1.01	
	WIDOWED	1.24	
RACE*MARITAL STATUS	BLACK DIVORCED	.95	
	BLACK UNWED	.74	*
	BLACK WED/SEPARATED	1.19	*
	BLACK WIDOWED	1.20	
	WHITE DIVORCED	1.06	
	WHITE UNWED	1.36	*
	WHITE WED/SEPARATED	.84	*
	WHITE WIDOWED	.83	
EDUCATION	UNDER 12 YEARS	1.14	*
	12 YEARS AND UP	.88	*

** ODDS RATIO FOR CIRCULATORY DISEASE VS. MALIGNANT NEOPLASMS

An Afternoon With Conference Cosponsors



DATA FOR AN AGING POPULATION

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AN AFTERNOON WITH CONFERENCE COSPONSORS

Manning Feinleib, M.D., Dr.P.H.
National Center for Health Statistics

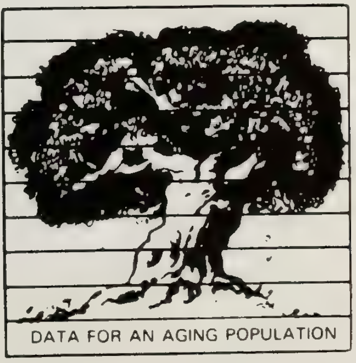
William P. Butz
U.S. Bureau of the Census

T. Franklin Williams, M.D.
National Institute on Aging

The program for this session was informal. Although it did not include the presentation of papers, it did include a description of key activities concerning data on aging conducted by each sponsoring agency. The participants were given the opportunity to ask questions about topics not covered in the formal sessions, such as collection, analysis, publication, and coordination of statistics about our aging population. The session was designed to meet the need for an exchange between Conference cosponsors and participants. All Conference participants were invited to participate.

Third Plenary Session

Analysis, Trends, and Projections


DATA FOR AN AGING POPULATION

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AGING IN THE 20th and 21st CENTURIES

Jacob A. Brody, University of Illinois at Chicago

Older people in the United States comprise a steadily increasing proportion of the total population which reflects the phenomenon that there is an increase in the absolute numbers of people over age 65 who simultaneously are living longer. This constellation has not been witnessed before. Longevity is our joy and our bane. Most medical needs, attention, and cost occur during the last years of life. The drama we are witnessing this century can be viewed insightfully, therefore, in terms of the age at which people are dying. In 1900 about 25% of people survived age 65. Clearly, medical and social attention was focused on young individuals who were dying of infectious diseases and other acute conditions. By 1985, appproximately 70% of deaths occurred in those 65 and over. Indeed, currently about 30% of deaths occur in people 80 years and over and almost 20% occur in people 85 and over (1). Our best efforts must now be diverted to an entirely different array of diseases, conditions and social structures which are involved when the vast majority of people survive through these older ages.

The age specific incidence or prevalence of diseases and interactive social conditions become the driving force in shaping our needs and responses. Thus we know that 25% of those surviving age 85 will have Alzheimer's Disease or a related dementia (2). By age 80 about 20% of our population resides in nursing homes (3). Life expectancy at birth is now 75 years. Thus one half our population survives beyond age 75 when half the people have some form of arthritis, more than 1/3 are hearing impaired, 15% have severe visual impairment, and heart disease occurs in more than 30%. We are slowly recognizing which diseases, conditions, and social structures are involved when the vast majority of people survive to these late ages. New needs and solutions will be introduced gradually and falteringly, largely through trial and error. We are involved with the development of an empirical body of knowledge which will instruct us. Humankind has no experience in dealing with a population this old and this large so our greatest efforts must be directed toward monitoring and describing the baffling transitions and reactions in order to be in a position to take useful and successful actions (4).

Mortality rates since 1900 (Figure 1) indicate the marked decline in mortality this century (5). Of note is that approximately half the gain in decreased mortality this century was accomplished by about 1920. This obviously was not influenced by medical progress or social policies but rather was a reflection of improved living conditions, sanitation and probably nutrition.

Of note is that those 65 and over, who as mentioned above accounted for only 25% of mortality in 1900, but by the 1980's was about 70% of all mortality, did not participate in the extraordinary decline in mortality in the first twenty years in this century. A decline of only 5% was noted in those 65 and over. The median point for the century, however, even for those 65 and over, occurred between 1945 and 1950. Thus very strong forces were driving mortality down among those 65 and over between 1920 and the late 1940's. The specific factors involved in this decline are not obvious. We experienced a remarkable period in American history which included World War II, Prohibition, the introduction of Social Security, the Great Depression and the New York Yankees winning most of the World Series. Perhaps during those periods the affects of medical and social policy became more pronounced but it would be difficult to believe that they determined the striking pattern of this curve.

Another puzzling feature of the mortality patterns this century is that from the mid-1940's until 1968 the curve remained flat. This contributed to a false sense of security that life expectancy had reached its maximum at about age 67 years and that further improvement was not to be anticipated (6). Possible reasons for this plateau are discussed elsewhere (5,7). It is obvious, however, that had we been following the data more carefully, and been better prepared to evaluate the patterns and sub currents, certain policies, particularly related to Social Security and Medicare, could have been thought through differently with far more beneficial results.

This forms a vital lesson from which we must learn. The story continues to unfold and as we all know, in about 1968 (Figure 1) Americans apparently eschewed dying. From that time to the present there has been a remarkable decline in death rates. The rates continue to decline to the present time and, although, we all concede that man is mortal and life-span is finite, we do not really know how to anticipate the speed and duration of this downward plunge.

Mortality declines since 1968 have occurred during a period in which we have become increasingly active in medical and social health issues. The major features observed are a sharp decline in mortality from heart disease and cerebral vascular disease, two conditions which account for more than half of all deaths. Efforts such as smoking cessation, exercising, jogging, alteration in diet and medications to control blood pressure must be having a positive effect. It would be a mistake, however, to claim that we either understand or are in control of the timing or size of the phenomenon observed since 1968 (8). Let us bare in mind that life expectancy at birth in Japan and Sweden exceed that in the United States. In those countries no sharp decline has occurred for heart disease or cerebral vascular disease and, in general, exercise, smoking cessation and reduction in fatty food consumption are not nearly as widely practiced as in the United States.

Since we are living longer we are obviously healthier at each age, but since we are living into increasingly old ages, we pay the price of multiple social and medical risks incurred with extended aging. This is the heart of the matter. In increasing longevity, we must discuss net gain in active functional years versus total years of disability and dysfunction. We are and will continue to place more and more people in older and older age groups. Our statistical measurements are sparse and crude, leaving us with gaps and guesses about how well or badly we are living during our increased years. In this area, where our data are weakest, the bulk of available evidence gives rise to pessimism (10,5, 11). Present data suggest that for each active functional year gained we add about 3.5 compromised years (9). And in the words of the English poet Andrew Marvell, (from his poem Coy Mistress) "But at my back I always hear time's winged chariot hurrying near" and we realize that in 2010, the infants of America's babyboom will begin to turn 65.

In order to understand the impact of gains in longevity we must undertake the dangerous business of population projections. The projections are, of course, more secure for the next twenty or thirty years and are accurate enough to be of great use through the middle of the 21st century. I use three specific examples to illustrate physical, mental and social realities that will occur unless major and unforeseen advances in science and health management develop. These illustrations simply reflect the projected demographic information with the age specific incidence or prevalence figures available to us now. In 1985 there were approximately 230,000 people who fractured their hips, with a median age of 79 years. By the year 2000 the number will rise to 340,000 and, making the leap forward to the year 2050, there will be 650,000 hip fractures (Figure 2). In our zeal to conserve resources and available hospital space, are we taking into account the fact that by the end of the century we will be treating in excess of 100,000 more hip fractures which are surgical emergencies and require surgical suites.

In Figure 3 are presented data for Alzheimer's Disease and related disorders, a much larger problem than hip fractures. At present median age for Alzheimer's Disease is about 80 years. There are currently about 2.4 million Americans with dementing disorders. By the year 2000 the number will rise to 3.8 million, and by 2050 there will be more than 8.5 million people with these conditions.

There are currently about 1.4 million people age 65 and over in nursing homes whose median age is about 80. By the year 2000 the number will rise to 2.2 million and in the year 2050 a conservative estimate projects the nursing home population to be 5.5 million (Figure 4). This estimate is conservative because we know that the numbers of people in nursing homes is dependent on available family and social situations to keep people out of nursing homes. We are faced with the reality that family size is shrinking and the usual support givers, particularly women, are in the work force. Between 1940 and 1979, the proportion of employed women rose from 11 to 55% (12).

Many issues in health, research and public policy will depend on a redirection of efforts to accumulate information which could improve and indeed alter the types of projects presented above. The crucial data we need are age specific incidence and prevalence rates for those conditions which effect the elderly such as hip fracture, blindness, deafness, dementia, loss of spouse or caregivers, and the general diminution of autonomy and functional ability. Compounding our lack of age specific data is the fact that old people have many conditions and diseases simultaneously and interactions rather than simple linear projections are poorly understood and probably require entirely new methodological approaches. We should not flinch at this. While advocating for public policy for now and into the 21st century, we must pause to reflect how we are doing and what it would require to do better and to be able to measure that we are doing better.

At present, we are concerned that the deluge of elderly people is already seriously over-taxing our nation's ability to respond, and at the same time we are limiting our ability to collect data and measure trends and outcomes. While we are not doing well, we must not avoid the fact that countries with far better developed national health policies are doing no better than we are. The greatest obstacle is failure to understand that evaluation research is difficult and perhaps new insights are necessary before we can enthusiastically embark on new national policy ventures. Despite the opinions of many serious commentators that we have no coherent health policy for our elderly, we are not doing badly in relation to the rest of the world in the measureable aspects of health and well being of elderly populations. The following slides illustrate my point. Among 17 of the most highly developed countries in the world who have been reporting to the World Health Statistics Annual from 1974 through 1985 observations which were surprising to me have arisen. Table 1 is a list of the 17 developed countries and their populations. In Figure 5 we see life expectancy in these countries for five year periods, from 1950 to the present. It is obvious that data concerning life expectancy at birth are a source of pride to the Japanese and not to Americans. During the time period observed, we consistently occupy a lower rank among developed nations while the Japanese have gone from the lowest to the highest ranking during this 35 year period. Life expectancy at age 65 (Figure 6) in the United States over the entire period of documentation was in the upper half of the 17 reporting countries. Strikingly, life expectancy at age 75 (Figure 7) is among the best in the world for Americans.

Two concepts emerge from these data. First, that all calculations involving international comparisons must be analyzed with some procedure to take into account age specific person years at risk in the elderly population. Second, we can see that 17 countries with widely diverse national policies and health and social services delivery systems do not differ very much in terms of mortality. If we are to engage in studies of critical issues of morbidity and life satisfaction/quality of life we must acknowledge how difficult the enterprise will be. We are, perhaps, on the threshold, or at least on the threshold of recognizing the need for defining measureable intermediate endpoints in order to monitor trends and to evaluate new technologies and policies as they are introduced. Money, time and thought must be expended to determine the age specific incidence and prevalence of age dependent diseases and conditions (13). These include blindness, dementia, arthritis, deafness and hip fracture. These data are critical, but most important is their integration on an age specific basis, with an array of information concerning co-morbidities, co-disabilities, loss of autonomy and attendant ability to perform daily functions, and alterations in social situations such as loss of spouse or caregiver and the availability of friends, family, and funds.

I am preaching pragmatism, patience, and political will. Time is our ally and there is a new energy to enhance the political will for more creative and equitable decisions about the mental and physical health of the elderly. This is largely derived from the fact that health care givers, politicians, and indeed most decision-makers now have first hand exposure, and will increasingly have more first hand exposure, to the good and bad involved in an increasingly aging society. The greater familiarity with problems such as arthritis and dementia and the anxieties of living alone, and the need to fill out incredible forms to secure payment and quality care, the greater becomes the likelihood for us to find better solutions.

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Figure 1

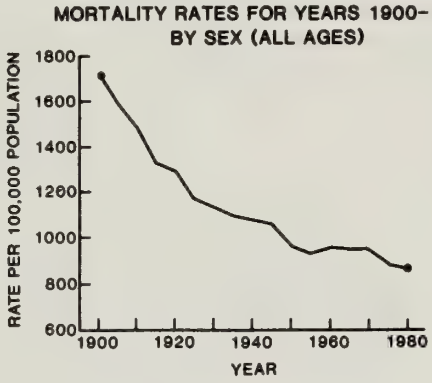
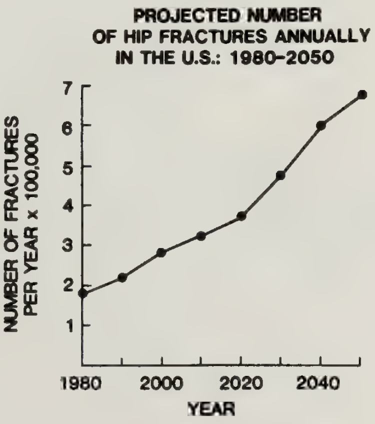


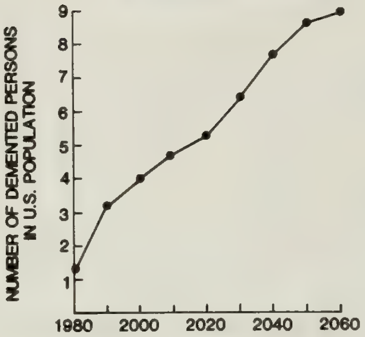
Figure 2



"Source: NCHS and U.S. Bureau of Census projections"

Figure 3

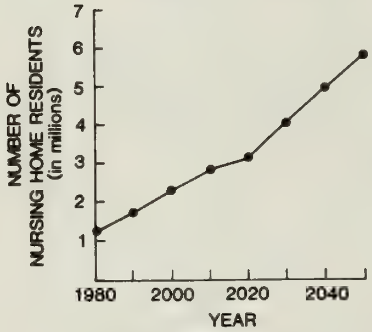
PROJECTED NUMBER OF DEMENTED PERSONS IN THE U.S.: 1980-2050



"Source: NIA prevalence estimates and U.S. Bureau of Census projections"

Figure 4

PROJECTED NUMBER OF NURSING HOME RESIDENTS IN THE U.S.: 1980-2050



"Source: NCHS and U.S. Bureau of Census projections"

Figure 5

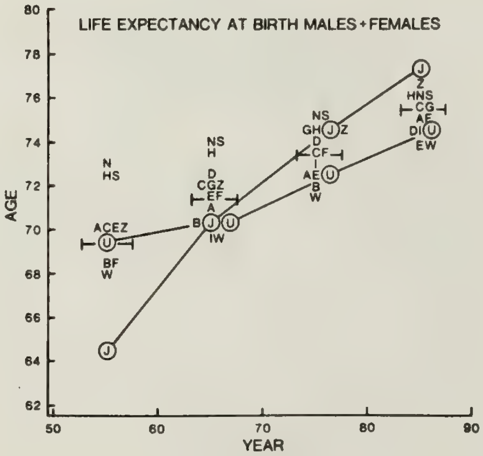


Figure 6

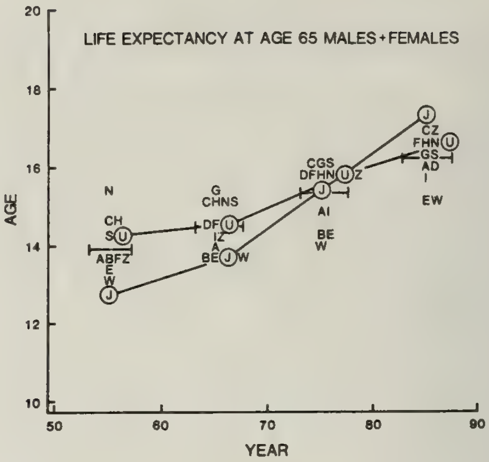


Figure 7

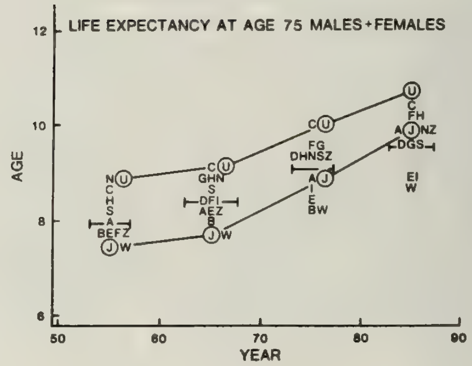


Table 1

Selected Countries, Letter Codes & Population

Letter Code	Country	Population in 1977 (millions)
A	Australia	13.8
B	Belgium	9.8
C	Canada	23.3
D	Denmark	5.1
E	England & Wales	49.3
F	France	53.3
G	Greece	9.2
H	Netherlands	13.8
I	Italy	56.5
J	Japan	113.8
N	Norway	4.0
S	Sweden	8.3
U	USA	215.6
W	West Germany	61.6
Z	Switzerland	6.3

AGING IN THE 21st CENTURY: PROJECTIONS, PERSONAL PREFERENCES, PUBLIC POLICIES: A CONSUMER VIEW

Anne R. Somers, University of Medicine and Dentistry of New Jersey-Robert Wood Johnson Medical School

I am not a demographer. I am not even a statistician. I have spent more than 35 years studying health and health care policies in the U.S. and other countries. Equally important, for more than 73 years I have experienced the results of such policies - or the lack of them. In my personal life and in that of my family I have experienced the triumphs and the failures of modern medicine; the positive and negative incentives to good health and efficient health care inherent in current U.S. health policies; the hope, the joy, the fear, and the despair of people in an aging society which has not yet decided whether we elderly are an asset or a liability; whether the "Geriatric Imperative" dictates an ever-growing burden on an already deficit-ridden nation or whether it offers opportunity for combining maturity, productivity, and compassion in a new approach to Aging in the 21st Century.

In this brief paper I will say why - on the basis of changing public and professional attitudes - I feel cautiously optimistic, even with respect to the difficult and neglected area of long-term care. But, first, a word about the Geriatric Imperative.

THE DEMOGRAPHIC REVOLUTION AND THE GERIATRIC IMPERATIVE

The dramatic demographic changes which underlie the Geriatric Imperative are now familiar: the 100 percent rise in median age of the population from around 16 in the early 1800s to 32 today (U.S. Bureau of the Census, 1984); the increased life expectancy at birth to nearly 75 years today (Health, United States, 1986) and at age 65 to nearly 17 years; the rise in number and proportion of elderly, including those over 75, even those over 85.

Progression from the current elderly ratio - 12 percent - to the 22 percent projected for the mid-21st Century will not be even, however. Until about 2010, when the World War II "Baby Boomers" begin to reach 65, the increase in number and proportion will be quite moderate, reaching only 13 percent in 2000. The dramatic expansion will come after 2010 - the period when the demographic revolution may, indeed, assume crisis proportions unless adequate adjustments are made in the meantime.

Projections into the next century depend, of course, on assumptions with respect to future mortality rates and life expectancy as well as fertility rates and immigration. Most importantly, how long will the recent dramatic decline in mortality rates continue? Will average life expectancy eventually stabilize in accordance with a more or less finite "normal human lifespan"? Projections differ widely on this point, depending on different assumptions and different definitions. In 1984, the Census Bureau projected an "ultimate life expectancy" for 2080 in the range of 77.4 to 85.9, with a middle figure of 81.0. Others have projected 100-110 (Butler, 1987). Fries projects a "normal lifespan" of about 85-86 with a standard deviation currently about 9 years, decreasing to 7 (Fries, 1987).

The 21st Century may be over before we know the final answer to the mystery of the "ultimate" or even the "normal" lifespan. The most recent figures from the National Center for Health Statistics suggest a slowing down of the rise in life expectancy, both at birth and at age 65. The provisional figure for 1985 - 74.7 - is precisely the same as for 1984, only the second year since 1972 that gains have been less than 0.1 a year, compared to gains ranging from 0.2 to 0.6 a year in the mid-1970s. At 65, the figure has remained stable at 16.8 from 1982 to 1985 (Health, United States, 1986).

Another straw-in-the-wind relates to the narrowing of the gap between male and female life expectancy. For several decades the gap was widening until in 1975 American women could expect to live 7.8 years longer than men. Since then, however, that difference has fallen to just 7 years, the result of slower improvement for women - probably due primarily to more smoking - and greater improvement for men. Similarly, the gap at age 65 narrowed from 4.3 years in 1975 to 4.0 in 1985.

Despite these potentially significant developments, reinforcing the hypothesis of a finite normal lifespan, we can certainly anticipate for the first half of the 21st Century - barring nuclear war or other major disaster - a rapidly growing number and proportion of individuals living into their 70s and 80s with a sizeable number of nonagenarians and even centenarians.

INCREASING PUBLIC MATURITY: OPTIMISM PLUS REALISM

How do older people view this prospect? Clearly, with mixed feelings! The optimistic view - probably held by the majority - is reflected in the sunny pages of Modern Maturity, the official magazine of the American Association of Retired Persons, distributed bimonthly to a reported membership of 25 million. Examination of the magazine's 58 feature articles for the past year - mid-1986 to mid-1987 - reveals the following breakdown by major category (admittedly somewhat arbitrary): Travel - 21 percent, Food/Festivals - 19 percent, Personal Finance/Retirement - 16 percent, Hobbies - 10 percent, Personal/Family Health - 7 percent, Profiles of Famous People - 7 percent, Arts, Nature and Public Policy - 5 percent each, All others - 5 percent.

Editorial policy firmly rejects not only "negative" articles but even "negative" advertising - "anything that shows old people in a bad light" (Currie, 1987). The most recent issue features an article on work and concluded - not with the traditional call for earlier retirement and better pensions but - with these words:

"Will more older people want to work in the future?

"Our answer is yes." (Bird, 1987)

A darker view reflects growing realization of the possibility of long-term chronic illness or disability, catastrophic expenses not covered by Medicare or Medigap insurance, dwindling family and neighborly supports, the possibility of having to "spend down" to welfare status, and increasing strains on those family members who are present. This view is reinforced not only by personal and family experience but by the increasing public attention to Alzheimers, Parkinsons, ALS, and other serious chronic diseases. Indeed, Alzheimers may have replaced cancer as the most dreaded disease and has become a metaphor for what people fear most about old age.

Concern for the "right to die," adoption of "living wills," and designation of a durable power of attorney for the purpose of making medical treatment decisions, are also increasing, reflecting growing public sophistication with respect to the risk of protracted illness and the need for advance planning to minimize unnecessary personal and family suffering and financial depletion. In a 1986 "Grey Paper," published by the Older Women's League and written mostly by Tish Sommers, first president of OWL, just three months before her own death, Ms. Sommers says,

> "Technological advances in medicine make us think about our own vulnerability and the circumstances we may face at the end of our lives. What if we are no longer able to make life or death decisions in our own behalf? What if we are kept alive by mechanical means long after our minds and our spirits have succumbed? What if we lose control of what happens to us?" (Sommers et al., 1986)

Tish Sommers has died but her voice will continue to contribute, as it has in the past, "to the development of social policy based on humane and realistic premises." As of 1987, 38 states legally recognize "living wills" and most of the others are considering such legislation (Society for the Right to Die, New York City, telephone communication, July 6, 1987). In one continuing care retirement community near Philadelphia, 75 percent of some 375 residents have signed living wills and designated a durable power of attorney for this purpose (Pennswood Village, Associate Director, unpublished information, July 6, 1987).

Reflecting this groundswell of public opinion, the New Jersey Supreme Court has just expanded the right of individuals to refuse life-sustaining medical treatment, saying the patients' interests must come before those of the state (Sullivan, New York Times, June 25, 1987). In the words of Justice Marie Garibaldi, who wrote the decision, "Questions of fate have become questions of choice" (Malcolm, New York Times, June 28, 1987).

Some health experts see a special irony in this situation: Precisely at the time that medical science, public health and education, improved nutrition and a generally higher standard of living have combined to produce the best life expectancy in U.S. history, an influential segment of the elderly - the presumed beneficiaries of this historic p.ogress - are focusing public attention on the "right to die."

PROFESSIONAL REINFORCEMENT

However, a shift of emphasis is also apparent in the new fields of Gerontology and Geriatric Medicine. There is, of course, major concern with the special problems of the very old and the severely disabled, including those with Alzheimers and related diseases, incontinence, decubiti, and general functional and financial dependence. This concern should - and I am sure will - continue. But, increasingly, professional interest is focusing on the prevention, postponement, or control of the major chronic diseases leading to disability and dependency. This is especially true of research.

One of the first geriatricians to stress the importance of prevention was Frank Williams, Director, NIA. As early as 1979, he wrote, "Many of the conditions that predispose the elderly to functional dependency are amenable to preventive intervention" (Filner and Williams, 1979).

The following year, James Fries, a rheumatologist from Stanford Medical School, published the first of several papers articulating the concept of "compression of morbidity," based on the assumption that the average age of incidence of serious chronic illness or disability can be pushed back further or faster than the average age of death (Fries, 1980, 1983, 1987).

The thesis is controversial since it challenges a fairly common assumption that improvement in age-specific mortality rates is likely to exceed improvement in morbidity rates and thus lead to more, rather than less, disability. While it is obviously true that the greater number of elderly in the population will, almost certainly, lead to more overall illness and disability, Fries maintains that this need not be so for morbidity and disability rates, that is, any given person need not anticipate more morbidity or disability. In defense of his view, he marshalls considerable documentation, including the following (Fries, 1987):

- Recently released morbidity data from the well-known Multiple Risk Factor Intervention Trial (MRFIT) shows much more impressive results from the preventive interventions - reduction of smoking, HBP, and serum cholesterol - in terms of morbidity as opposed to mortality. Whereas the interventions reduced coronary deaths in the treatment group by only 7 percent and failed to reduce total deaths at all, the eight morbidity measures used fell by an average of 23 percent (MRFIT, 1986).
- The Lipid Research Clinics coronary prevention trial, another massive randomized study, examined the effect of a drug, cholestyramine, on total serum cholesterol. This trial also failed to reduce total deaths significantly but morbidity fell by 20 percent (Lipid Research Clinic, 1984).
- Studies of osteoporosis have projected that osteoporotic fractures could be reduced by 50 percent by the mid-21st Century if only currently available preventive techniques were adequately used (Brody, 1985). Other researchers have demonstrated significantly increased bone density in regular runners over age of 50 after careful matching with community controls (Lane et al., 1986).

Reflecting the potential improvement in health status suggested by these studies, Fries maintains that the age-specific incidence of chronic disease is already declining. For example, Pell and Fayerweather found a 28 percent drop in the age-specific incidence rates of myocardial infarction among male employees of the Dupont Company over a 20-year period (Pell and Fayerweather, 1985). In contrast, 24-hour and 30-day case fatality rates remained approximately constant. Analysis of short-term hospital stays in U.S. hospitals over a 13-year period suggests that the average age of hospitalization for cardiovascular disease increased more rapidly - an average of 4 years - than did life expectancy - 2 years - over the same period (Fries, 1987).

While it is true that "trade-offs" between morbidity and mortality will continue to occur, occasionally resulting in prolonged disability and higher overall costs, Fries maintains the opposite is more likely to be the case, as demonstrated by recent experience with heart disease and lung cancer. Moreover, many disabling diseases, such as osteoarthritis and back pain, are rarely fatal and any reduction in incidence in these areas clearly contributes to the net reduction in morbidity. Even in the case of morbidity associated with senescence - e.g. failing eyesight and hearing, osteoporosis, fractures, dental problems - preventive or corrective measures are frequently available.

It is not the purpose of this paper to reopen old controversies between the advocates and opponents of the "compression of morbidity" thesis. I join heartily with Dr. Brody and others at this conference in urging the need for more data and greater research attention to the relation between specific risk-factors and the age-specific incidence of morbidity/disability from specific diseases, as well as the relation between specific preventive interventions and health outcomes. Meanwhile, it is my purpose to state, as a consumer/patient, that the concept encapsulates - albeit in rather obscure language - what most people pray for - the longest possible healthy life followed by a quick death (preferably not a violent one). I also want to emphasize that this approach appears in line with a number of important related concepts and programs that have emerged in the past few years from a number of separate individuals or groups.

1. "Preventive Gerontology" is the intriguing concept advanced by William Hazzard, formerly of Johns Hopkins, now Chairman, Department of Medicine, Bowman Gray School of Medicine. Hazzard defines "Preventive Gerontology" as "the attenuation of time- and age-related processes to the extent that they fail to become symptomatic until the person approaches the upper limit of the human life span" (Hazzard, 1983). Whereas Fries concentrates on broad policy implications, Hazzard focuses on the individual physician and challenges him/her to a three-part role in the prevention of chronic disease: (a) a personal evaluation of the scientific data base from which individual preventive strategies are derived; (b) support for general community preventive programs, including living up to a preventive role-model; and (c) development of a consistent pattern or style of professional practice with individualized intervention strategies for individual patients.

2. "Productive Aging" is the term coined by Robert Butler, former Director, National Institute on Aging, now Chairman, Department of Geriatrics and Adult Development, Mt. Sinai School of Medicine, N.Y.C., to stress "mobilization of the productive potential of the elders of society" (Butler and Gleason, 1985). First elaborated at a Salzburg International Seminar in 1983, now institutionalized in The Center for Productive Aging which is part of the Mt. Sinai Department of Geriatrics, the concept and its implications achieved international attention at a conference entitled "The Promise of Productive Aging: The Future for Japan and the U.S." held in Washington, April 1987 and sponsored jointly by Mt. Sinai Medical Center, the Japan Shipbuilding Industry Foundation, and the Alliance for Aging Research.

Both the Salzburg and the Washington conferences started by emphasizing the science base for the potential of "productive aging." A. Svanborg of Sweden documented the fact that recent cohorts of Swedish 70-year olds are healthier and more able than their predecessors. "While the risk of falling ill does increase in old age, more years of relative health have been added to average life expectancy" (Butler and Gleason, 1985). James Birren, former Dean, Leonard Davis School of Gerontology, University of Southern California, documented the persistence of mental competence even into old age:

> "While becoming more vulnerable to disease, the individual may generate new roles, develop new concepts and perceptions of self and society, and take up new careers and vocations. . . . The performance of the brain is an example. The normal brain remains active throughout life, but the diseased brain loses information. Birren's outlook implies that aging at the social and psychological levels is highly malleable." (Butler and Gleason, 1985)

Out of the Salzburg Seminar, there emerged a set of Principles. The first two of these were as follows:

> "Health care should enable people to function to the limit of their physical, psychological, and social capacities. Therefore, care that emphasizes health promotion, disease prevention, and integration of services is preferred over institutionalization. Any services that induce dependency should be discouraged.
>
> "Productive participation in society is essential to health."

3. "The Disuse Syndrome" is a term coined by Walter Bortz of the Palo Alto Medical Foundation, California. According to Bortz:

> "The identifying characteristics are cardiovascular vulnerability, obesity, musculoskeletal fragility, depression and premature aging. The syndrome is experimentally reproducible and the clinical features are subject to both preventive and restitutive efforts that are happily cheap, safe, accessible and effective." (Bortz, 1984)

4. "Successful Aging" is the title given to

a multi-million dollar research project funded by the MacArthur Foundation and directed by John Rowe of Harvard Medical School. The study involves a long-term effort to identify the causes and "predictors" of "successful aging" and hopes to produce a "risk profile" to facilitate early positive intervention in the aging process (MacArthur, 1985).

5. In 1982, the Carnegie Corporation of New York established an "Aging Society" Project which resulted in the book, Our Aging Society: Paradox and Promise (Pifer and Bronte, 1986). Among its important findings was "the unexpected and unexplained extension of the adult prime" (L. Bronte, Presentation, Monmouth Medical Center, Long Branch, N.J., May 28, 1987).

6. Finally, of special interest to this audience of sophisticated statisticians, actuaries, and other technical experts is the concept of "active life expectancy" developed by Dr. Sidney Katz and colleagues (Katz et al., 1983). "Instead of death, the end point of an alternative active life expectancy is loss of independence in the activities of daily living," as measured by the ADL index. The authors believe the new measure can be used for both actuarial and epidemiological purposes including identification of high-risk populations for which preventive health and medical care can compress morbidity during the last years of life.

There are, of course, major distinctions between these concepts or programs. One is primarily methodological; two are addressed primarily to practicing physicians; one is a basic science research project; the others involve various aspects of public policy. But what they have in common is an emphasis on aging as a positive - rather than a negative - process, on the ability of the elderly simultaneously to promote their own health and contribute actively to society, and on society's ability to promote individual health and minimize dependency through timely preventive interventions.

PUBLIC POLICY: SOME IMPLICATIONS FOR THE GROWING LONG-TERM CARE INSURANCE DEBATE

It is time, now, to return to my original theme, "Projections, Personal Preferences and Public Policy" and to repeat the question raised at the outset, "Does the Geriatric Imperative dictate an ever-growing burden on an already deficit-ridden nation or does it offer opportunity for combining greater maturity, productivity, and compassion in a new approach to Aging in the 21st Century?"

I hope I have made clear my belief that we do have this opportunity and that I am joined in this belief by some of the most distinguished geriatricians and gerontologists in America. At the same time, I must emphasize that this positive approach remains a policy option, not a prediction. Inadequate conviction, inadequate resources, inadequate courage, even inadequate data, above all, inadequate vision, or just plain selfishness - on the part of the elderly as well as the young - could result in failure by default and lead to the type of self-defeating intergenerational conflict and stalemate already predicted by some pessimists.

This is not the place even to try to spell out the many changes in U.S. social policy that will be needed to assure a positive response to the Geriatric Imperative. I conclude with three broad statements of principle which summarize my overall approach as I contemplate the difficult policy debates that lie ahead.

1. Life involves a complex network of mutually supporting rights and responsibilities on the part of both the individual and society. In our large, complex, heterogeneous, and highly organized democracy, the relation between rights and responsibilities often becomes attenuated and at times almost disappears from view. In the last analysis, however, we ignore this relationship at our peril.

2. U.S. Aging Policy, as in other areas, must reflect this balance of rights and responsibilities. The inevitably large costs of providing high-quality acute and long-term care to the elderly must be accompanied by an obligation on our part (I speak as an elderly consumer myself) to take the best possible care of our own health and to remain active, productive (I do not shy away from Dr. Butler's term) and a contributing member of society as long as possible. This is particularly appropriate since we now know that health, activity, and productivity are generally complementary, rather than antithetical.

3. Focusing specifically on long-term care, the major gap in health protection for the elderly today, this suggests the need for linking the increased financial protection, so badly needed, to increased emphasis on health promotion and disease prevention. This can be done in various ways - some direct, some indirect. Elsewhere, I have suggested varying Medicare Part B premiums by $1-2 a month based on smoking status (Somers, 1984); or varying private long-term care insurance premiums by smoking status and perhaps other risk-factors for chronic disease or injury such as use of seat belts, smoke detectors in home, control of high blood pressure if present, moderate exercise, corrected vision if necessary, etc. (Somers, 1986). The "sin taxes" - on tobacco and alcohol - could be increased and the revenues specifically earmarked for long-term care benefits. The counter arguments are familiar - "blaming the victim," "excise taxes are repressive," etc. But the alternative may well be no significant progress in long-term care benefits as well as continued erosion of Medicare's acute care benefits. Conversely, to the extent that we do reduce the rate of incidence of cardiovascular disease, cancer, osteoporosis, emphysema, auto accidents, violence, and other preventable diseases and injuries, and the disability resulting therefrom, it is obvious that we can provide more adequate protection to the victims of Alzheimers and other conditions that we do not now know how to prevent.

Similarly, if the average age of retirement could be pushed back even a year or two we could provide more adequate Social Security and other pensions when they are really needed. The major argument against this used to be unemployment. But the coming labor shortage, reflecting the "Baby Bust" generation, combined with the changing nature of the American economy, with its shift from heavy industry to service jobs, make it both more urgent and easier for older people to continue healthy, active, and productive as long as possible and thus contribute to the good health care most of us will need and want before we die.

On all these issues, the need for reliable data, upon which to base our evolving policies for Aging in the 21st Century, is obvious and crucial.

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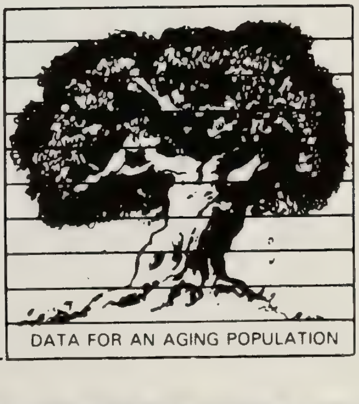
Session U

Methodology for Analyzing Data on Older Persons


DATA FOR AN AGING POPULATION

CONVERGENCE HYPOTHESES MODELED AND TESTED WITH LINEAR STRUCTURAL EQUATIONS

Jack McArdle, Edward Anderson & Mark Aber
University of Virginia

ABSTRACT: A method for piecing together separate longitudinal datasets into a single longitudinal function was termed "convergence" by R.Q. Bell (1953, 1954). This has been popularized as the cross-sequential design and is typically analyzed by ANOVA techniques. In this paper we use the techniques of Horn & McArdle (1980) and Meredith & Tisak (1984) to illustrate how linear structural equation modeling can be used to add some useful statistical features to convergence analyses.

1. INTRODUCTION

Over three decades ago Richard Q. Bell (1953, 1954) proposed to accelerate the collection of longitudinal information: "The method called 'convergence' has been advocated as a means of meeting some research needs not satisfied by either a cross-sectional or longitudinal approach. This method consists of making limited remeasurements of cross-sectional groups so that temporally overlapping measurements of older and younger subjects are provided. The remeasurements may be used as a way of determining whether trends which would otherwise be seen only between different age groups are corroborated within short time periods for each age group. The method may also provide a means of actually linking up individuals or sub-groups between adjacent segments of a developmental curve, each segment consisting of a limited longitudinal study on a different age group" (Bell, 1954, p.281). The efficiency of this technique was demonstrated by Bell (1954) who showed that a ten year longitudinal curve span could be approximated with only three years of data collection. Bell's seminal ideas are the foundation for contemporary "age by cohort" and "cohort-sequential" analyses (see Nesselroade & Baltes, 1979).

The statistical basis of the convergence model is not yet clear. In order to link up the information from different curve segments Bell (1954) used a D-index to match different individuals between different curve segments, but this was described by Bell as an ad hoc statistical technique. Recent treatments of this problem have promoted ANOVA and regression techniques, but these have been criticized (Nessselroade & Baltes, 1979; Horn & McArdle, 1980). The statistical problems associated with these analyses remain controversial at best.

In this presentation we illustrate how the statistical techniques of linear structural equation modeling (e.g., LISREL; Joreskog & Sorbom, 1984; COSAN; McDonald, 1986; RAM; McArdle & McDonald, 1984) can be applied to model and test Bell's convergence hypotheses. By fitting longitudinal growth curve models to multiple age groups, we test hypotheses about age and cohort convergence. To illustrate these basic points we fit a subset of structural models previously defined by Horn & McArdle (1980), Meredith & Tisak (1984) and McArdle (1986, 1987a,) to a selected set of longitudinal and cross-sectional WAIS data provided by Botwinick & Siegler (1980).

2. STRUCTURAL EQUATION MODELS

The techniques of linear structural equation modeling are well known and widely used in aging research (see Loehlin, 1987; Blalock, 1986). The LISREL notation and computer program of Joreskog & Sorbom (1984) have become popular for longitudinal data analysis. In many cases these analyses have been geared toward the causal analysis of time series (Joreskog in Nesselroade & Baltes, 1979; but, see Rogosa & Willet, 1985). Horn & McArdle (1980) used these ideas to analyze a complex mixture of longitudinal and cross-sectional data. Recently Meredith and his colleagues (see Meredith & Tisak, 1984; McArdle, 1986; McArdle & Epstein, 1987) have demonstrated how a wide variety of growth curve concepts can be modeled using standard structural equation techniques. In this presentation we illustrate some of this recent work.

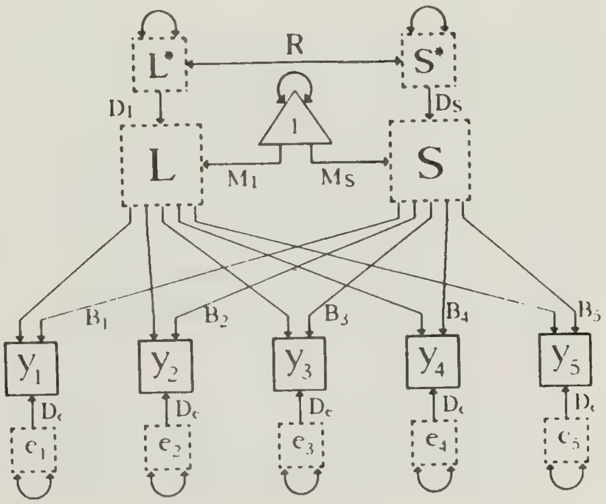


Fig. 1: A Structural "Growth" Model

Figure [1] is a path diagram of the longitudinal structural model we term a "growth model". In this path model we assume that n=1 to N individuals have been measured over t=1 to T occasions on one measured variable termed y. For each individual at each time we write

[1] $y_{t,n} = L_n + B_t S_n + e_{t,n}$,

where the coefficient B_t is a Basis or function of age-at-time-t, and the variables L represent individual differences in "levels" common to all times, S represents individual differences in "shapes" common to all times, and e_t represents an "error" or "disturbance" term specific to each occasion. In Figure [1] we draw the observed y scores in "closed boxes" and all unobserved components as "open boxes". We also draw all coefficients as one-headed "arrows" or projections.

This growth model is completed by writing

[2] $L_n = M_L 1_n + D_L L^*$,

$S_n = M_S 1_n + D_S S^*$,

$e_n = D_e e^*$,

$E\{ L^* L^{*\prime} \} = E\{ S^* S^{*\prime}\} = E\{ e^* e^{*\prime}\} = 1$,

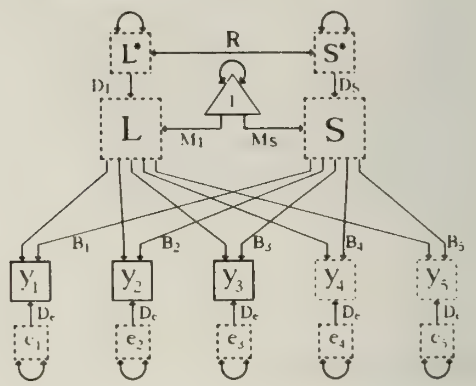
and $E\{ L^* S^{*\prime}\} = R(L,S)$,

where 1_n is the unit constant (drawn as a triangle), M_v are means or location parameters, D_v are standard deviations or scaling parameters, the asterisk v^* indicates standardized scalings of the latent scores (for v = L,S and e), and E{ } denotes the expected value operator. All latent components are assumed to be independent except for the correlation among the levels and shapes scores, called $R_{L,S}$, and drawn as a two-headed "sling" between L^* and S^*.

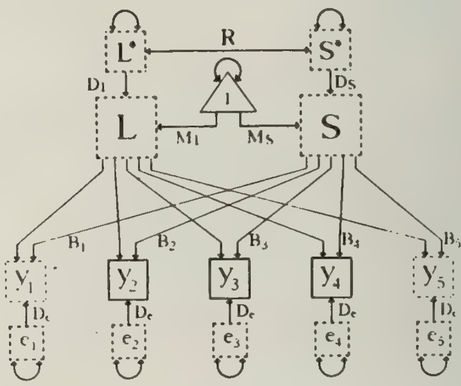
This growth model [1] and [2] may be fit to any univariate repeated measures series of sufficient length (usually T > 3). The mathematical and statistical basis is developed from well-known structural equation theory except for a few special details. One exception is the inclusion of model means which requires the model to be fit to both means and covariances. One popular way to do this is to enter a moment matrix of raw cross-products with an additional unit variable (drawn here as a closed triangle). In these cases the maximum likelihood function is defined as

[3] $LRT = -2N \ln LR$
$= N [LR(d) + LR(t) + LR(m)]$,
with $LR(d) = \ln| C^* | - \ln| C |$,
$LR(t) = tr [C C^{*-1}] - T$,
$LR(m) = [m - m^*]' C^{*-1} [m - m^*]$

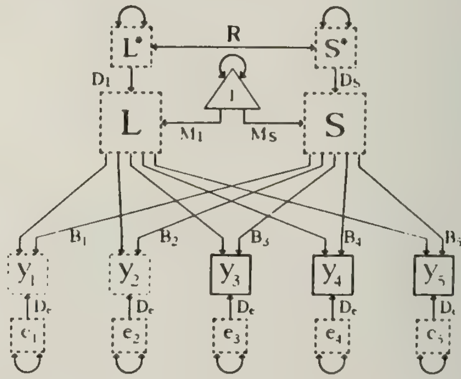
where C and m are the observed covariances and means obtained from the data, C* and m* are the covariances expected by the model, and where the determinant LR(d), trace LR(t), and mean LR(m) components of the LRT are separated (for more details see Sorbom in Joreskog & Sorbom, 1984; McArdle, 1986, 1987b). The model is interpreted as reproducing average cross-products and all GOF indices need to be evaluated in this metric.



Group 1



Group 2



Group 3

Fig. 2: A Multiple Group Age-convergence Growth Model

The second exception in this convergence problem comes because the data are collected on independent groups and the groups are measured at different times. The multiple group path diagram in Figure [2] illustrates one generic solution to this problem. Here we presume the same path model in all groups, but each dataset is assumed to have different latent or "hidden" variables h_t. In Figure [2], the first group is missing the last two scores Y_4 and Y_5, the second is missing both Y_1 and Y_5, and the third is missing both Y_1 and Y_2. The key statistical feature is that the MLE are built up from available information across all three groups simultaneously, but the groups have different sections of missing and overlapping data. In general, we simply treat these hidden variables as any other latent variable in any other model, including the problems of identification, but we deploy these h_t throughout the model to conform to the convergence data design. This allows us to test hypotheses about convergence across separate groups by using standard techniques for testing the invariance of factor loadings across groups (see Nesselroade, 1983).

3. NUMERICAL ILLUSTRATION

To illustrate this convergence model we use the data design and analyses originally reported by Botwinik & Siegler (1980). In this research four age cohorts who were tested at least four times were selected from the original Duke Longitudinal Study of $N=287$. At the initial testing the four groups were aged 60-63, 64-67, 68-71 and 72-75. Botwinick & Seigler report several WAIS scores for each of four longitudinal occasions of measurement. These groups were also chosen so that the time-of-measurement and age-of-testing were appropriately "staggered"; e.g., the average age of the first group at the second measurement is approximately the average age of second group at the first measurement.

In this analysis we examine these four groups measured over four occasions but we use only the WAIS Digit Symbol Substitution task scores from a total $N=91$. Figure [3] plots the means and standard errors for each of the four groups over four occasions of measurement. This figure displays the summary statistics for the original DSS divided by the maximum score of 90; viz, the "percent correct" metric simply reflects Digits Per Second (DPS). The longitudinal means for each group are plotted against the age-of-testing to demonstrate the age convergence design. Most critically, the data was collected during only a 12 year span but the subjects' age span covers 23 years.

The analysis is set up as a four group model where each group has the same model but a different set of data based on $T=4$ (see Figure [2]). This is easily represented in current computer programs like LISREL by using RAM notation with a changing filter matrix. In all structural models to follow the factor loading coefficients for the B_t are set equal to the actual age-at-testing A_t. This setting of $B_t=A_t$ forces the shapes to be linear over the entire age range so we now use the term "slopes." Because the number of occasions $T > 2$, we obtain numerous degrees-of-freedom (DF) to test this linear hypothesis. This assumption of linearity is not required but seems acceptable in this example. Likewise, the disturbance term D_e is not required to be equal over time but for simplicity we will use this restriction in all models. The critical model parameters listed are the latent means M_L and M_S the latent

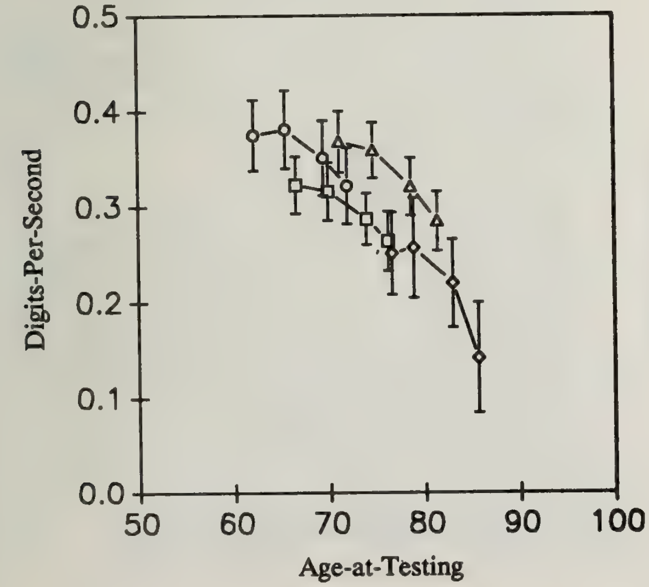


Fig. 3: Observed Statistics on Digits per Second over Age

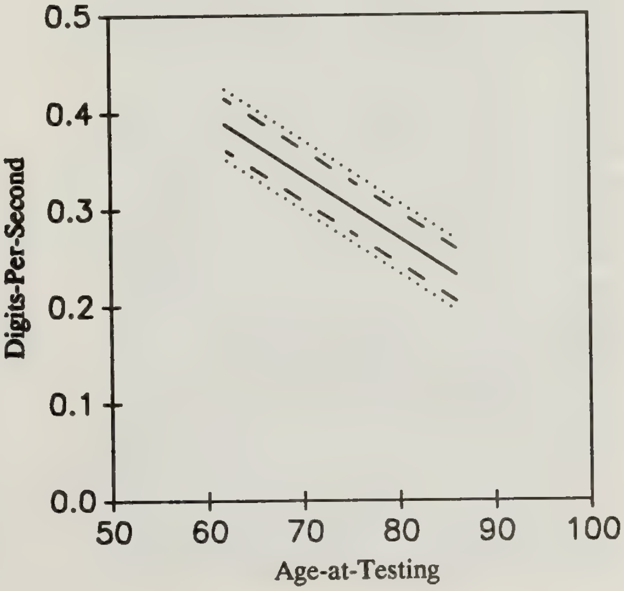


Fig. 4: Expected Statistics from the Age-convergence G* Model

standard deviations D_L, D_S, and D_e, and the correlation $R_{L,S}$. The goodness-of-fit indices here include the LRT and the DF for each model, and these can be compared to a chi-square variate with a Z statistic indicating departure from perfect fit. Differences between various models can be examined using differences in LRT and differences in DF with a corresponding difference Z. Other goodness-of-fit indices are relevant but are not needed to make our main point now.

The hypothesis of convergence across groups is simple because only one set of parameters M_L, M_S, D_L, D_S, D_e, and $B_t = A_t$ are needed to account for all data. In these data the age A_t ranges from 62 to 85 in an unequal interval. The Basis loadings B_t could be fixed at these numerical values. However, we usually adjust the center point and rescale the basis. Here

[4] $A_t = \{ 62, 67, 70, 74, 78, 82, 85 \}$, so
$B_t = (A_t - A_T) / A_T$
$= \{ -.271, -.212, -.177, -.129, -.094, -.041, 0 \}$,

and this B_t is the fixed reference point for L and S. The maximum likelihood estimates (MLE) and Standard Errors (SE) of the free parameters were then estimated by combining and weighting the information from the different groups. We obtain MLEs (and SEs) of

[5] $M_L = .238\ (.02)$, $M_S = -.556\ (.07)$,
$D_L = .174\ (.02)$, $D_S = .440\ (.08)$,
$D_e = .045\ (.01)$, $R_{L,S} = -.377\ (.15)$,

and these results can be interpreted as a single age curve for all four groups.

In Figure [4] we plot this expected curve in Cartesian coordinates. This curve is composed of three individual difference components: The initial Level and linear Slope, which are common to all occasions, and the occasion specific Error. The means of these components give the basic location of the curve within the coordinate space and the variance of these components gives the scatter around this location. In this model, the mean level of .238 gives the score of the DPS at age 85. The mean slope of -.556 shows the change in this level for each age. The level deviation of .174 is constant over all occasions but the slope deviation of .440 alters this scatter depending on the age basis. The specific error deviation of .045 is relatively small, so the growth reliability is high. The correlation of -.377 is a function of the reference point for Level chosen. As is shown in Figure [4], this is a smooth curve which declines rapidly over the 23 year period from age 62 to 85.

The hypothesis of convergence is simple so it may not fit these data. In the model above, we assume a single linear curve which is identical or invariant across all groups. The fit of this model yields LRT = 91 on DF = 53. This translates into a Z = 3.11 which is a normal deviate for the null hypothesis of zero residual cross-products. In a second model we fit the basic linear model of Figure [1] to each group separately. This second model presumes the linearity of each function within each group but does not require convergence across separate groups. This model fits these data with LRT = 72 on DF = 35, and yields a Z = 3.49.

The direct comparison of the first two models provides a formal test of the hypothesis that the groups are convergent with respect to a linear aging process. To distinguish between these two linear models we will denote the separate groups growth model as G and the convergent model as G^*. The difference between these models is indexed by the difference in the DFs, so DF = 18, and the difference in fit is indexed by the difference in LRTs, so dLRT = 19, and this yields a dZ = .27. By most reasonable statistical standards the two models G and G^* fit the available data equally well. We take this to mean that the separate curves for the cohorts can be considered convergent with respect to age.

Some additional models may provide useful information. One such model, termed A, is a composite model which is both linear in growth and has first-order autoregressive features among the disturbances. This model can be drawn from Figure [2] by adding directed arrows from e_t to e_{t+1} between adjacent time points. This model might be indicative of a linear growth process which includes a retest or memory effect which are specific between occasions (see Joreskog, 1979). This composite or Duplex model fits the separate groups with Z = 2.96. The A^* model adds the convergence assumptions with respect to the growth functions over age but not with respect to the autoregressive time functions. The A^* yields Z = 2.39 and the convergence hypothesis under this structure gives dZ = -.24. The improvement of this A^* model over the L^* model is indexed by dZ = 2.74.

We can add retest effects in many other ways: Model R adds a specific retest effect to the basic linear model by allowing the second slope loading within each group to have an additional value R. This form of retest assumes the basic shape of the slope is altered at the second time by virtue of having taken the test once before. Most critically, this retest alteration occurs only at the second time of measurement and is the same extra shift for all ages at the second test. This R model fitted to separate groups yields Z = 2.82, the R^* convergence model fits with Z = 2.35, and the convergence dZ = -.06. The improvement of R^* over L^* yields dZ = 3.21, but the extra parameter R = .035 is small.

In a final Model N we try to simplify the G model by eliminating all individual differences in slopes. The Model N yields Z = 7.70, the Model N* yields Z = 7.57, and the convergence dZ= .99. The direct comparison of N* to G* gives dZ=7.93. These values demonstrate that this "no growth" model is a rather bad idea for these data. We mainly use Model N* as a baseline upon which to judge the fit of the better models.

The overall convergence hypotheses is more clearly displayed in the plot of Figure [5]. In this figure we plot the LRT as a function of the DF for each model fit. The diagonal line is an expected information or penalty line. In these data, and with these models, the regression line through the origin yields b=(LRT/DF)=2.22, so, on average, each DF is expected to yield 2.22 LRT units (see McArdle, 1987b). The models above the line, (N and N*,) are not very good, the models on the line, (G, A, and R,) are average, and the models below the line, (G*, A*, and R*,) are our best models. We interpret these results to show that convergence is achieved within these groups on this variable. The plot also shows that there is just a small difference between the simple G* model and the more complex retest models A* and R*. To some small degree these differences also show that tests of convergence depend on the background conditions under which the hypothesis is tested.

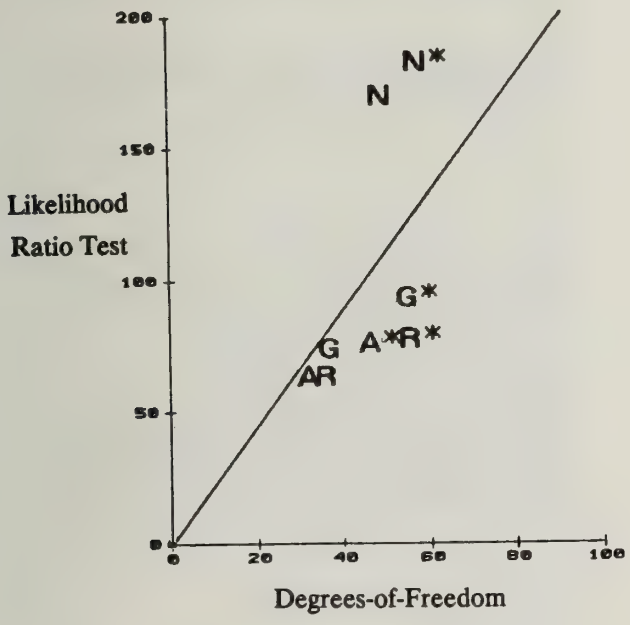


Fig. 5: The Goodness-of-Fit of Various Models

4. DISCUSSION AND SUMMARY

The main substantive result is clear. In this sampling of healthy elderly individuals a rapidly decreasing function for digits per second (DPS) was convergent over cohorts. The DPS variable is usually considered an indicator of general speediness, or G_s in Horn's (see Horn & McArdle, 1980) notation. We may assume that this result conforms to the overall decline of G_s in the elderly. However, the univariate model used here does not separate the reliability of measurement within each occasion from the reliability of growth across occasions. At the very least a multivariate model is needed in order to separate the G_s changes from the DPS changes over age (see McArdle, 1987a).

These results illustrate the available methodology for modeling and testing ideas about convergence of curves over age. The use of structural equation modeling techniques turns out to be efficient from both a statistical and practical point of view. In this view, convergence is not a necessary feature of data, but is a statistically rejectable hypothesis. The main advantage of the model is that the invariance constraints are clear and testable.

This logic further exposes several disadvantages or limitations of the model: Convergence is testable only where the groups overlap. This principle was clearly recognized by Bell (1954) who cautiously noted that the convergence method "will introduce considerable error into data collected, and that in some instances it might produce quite misleading results" (p.283). Furthermore, our assumption of a fixed age A_t for each cross-classification is required by [1] here, but this may be unrealistic. More recent work on the use of "continuous missing data" is more difficult to apply in practice but more realistic in theory (see Little & Rubin, 1987) In general, the special experimental design feature of overlapping cohorts needs to be considered before taking these kinds of modeling results seriously.

The present model is one reparameterization of a repeated measures MANOVA model with missing data. But now, using the same technology, we can examine: (1) within a dataset the convergence of some variables but not others; (2) the convergence of some age functions but not others; (3) a "latent" growth curve from the estimation of B_t; (4) "phase-shifts" with the addition of multiplicative parameters; (5) pre-defined groups to study "group differences" and non-random "selection"; (6) other individual difference variables for "causal" analysis of the determinants of growth; and (7) multiple variables for the discovery of multivariate growth "processes". (for examples, see Meredith & Tisak, 1984; McArdle, 1986, 1987a, 1987b; McArdle & Epstein, 1987). This report is but a small illustration of these future possibilities for structural convergence models.

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Footnote:

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USING THE LONG TERM CARE SURVEYS: LONGITUDINAL AND CROSS-SECTIONAL ANALYSES OF DISABLED OLDER PEOPLE

Judith D. Kasper, The Johns Hopkins University

This paper is intended to serve as an introduction to the Long Term Care Surveys, a unique source of information on a large population of elderly people with functional limitations. It will describe the design and content of these surveys, why they were conducted, what types of analyses are particularly suited to these data, and their limitations. At the beginning I would like to make two acknowledgements. One is to the Office of Research at the Health Care Financing Administration (HCFA) where I was an analyst when I agreed to give this paper. HCFA is one of the sponsors of both the 1982 and 1984 Long Term Care Surveys and the Office of Research provided support for the completion of this paper. The second acknowledgement is to Dr. Kenneth Manton and Michael Carney of Duke University who are preparing the public use version of these data and provided advice and technical assistance concerning the surveys. I would recommend that anyone planning to use these data obtain a copy of the paper by Kenneth Manton and Korbin Liu presented at a recent conference on long term care data bases (Manton and Liu, 1987).

The Long Term Care Surveys are two surveys conducted in 1982 and 1984 which form a data set containing extensive information about elderly people with functional limitations. In 1980 a Task Force on Long Term Care within the Department of Health and Human Services recommended a wide variety of data collection activities and analyses to provide the information base for formulating policy on long term care. Among the gaps identified was the lack of nationally representative data on who uses informal, community and institutional long term care services, patterns of use and how these services are financed. Surveys of health care use and expenditures representative of the nation as a whole often have too few people using long term care services for extensive analysis. In particular, elderly people beyond 70 or 80 years of age, who are most likely to experience problems in functioning that require such services, often are not represented in sufficient numbers. Partly as an outgrowth of this effort, HCFA and the Office of the Assistant Secretary of Planning and Evaluation (ASPE) cosponsored the 1982 Long Term Care Survey. In 1984 a followup survey was conducted with expanded representation of elderly people beyond the group interviewed in 1982. The 1984 survey was cosponsored by HCFA and the National Center for Health Services Research.

Design

Since the intention was to collect data concerning long term care services it was necessary to identify a population at high risk for using these services. This was done through screening thirty-six thousand people 65 or older whose names were drawn from the Medicare files in April, 1982. These people were contacted by phone or in person and asked questions to identify those with a limitation in either an Activity of Daily Living (ADL) or an Instrumental Activity of Daily Living (IADL), lasting or expected to last 3 months or longer. The approximately 6,400 people with such a limitation who were still living in the community were interviewed beginning in May, 1982. A companion survey of a sample of individuals who provided unpaid assistance to this disabled population was conducted following the 1982 survey (see Stone, Cafferata and Sangl, 1986).

The 1984 survey reinterviewed those from the original sample still living in the community. In the case of institutionalization or death, data were obtained from nursing home staff or next-of-kin respectively. In addition, several other groups were added to the 1984 sample. First, a sample of people who reported no limitations in 1982 were rescreened in 1984. Those now reporting a functional limitation were interviewed. Data were obtained as well if by 1984 the individual were institutionalized or deceased. Second, a sample of individuals institutionalized in 1982 were included in the 1984 sample and data were collected on their status in 1984, (whether institutionalized, deceased or living in the community). Third, a sample of people who turned 65 between 1982 and 1984 were included.

The design of the 1984 survey was intended to yield a data base that could be analyzed longitudinally (for persons in both 1982 and 1984) and cross-sectionally.

Table 1 illustrates the relationship between the 1982 and 1984 populations. The 1982 population consists of the 6,393 individuals identified as disabled and living in the community. (There is limited information from the screener concerning those who screened out because they were not disabled or no longer lived in the community.) The 1984 population consists of four groups: 1) the 6,393 from 1982--4,114 or 64 percent of whom were still living in the community, the remainder having died, been institutionalized or reporting no disability, 2) 12,100 individuals who were not disabled in the 1982 sample, 3) 1,992 people who were institutionalized in the 1982 sample and 4) 4,916 individuals who became Medicare-eligible between 1982 and 1984. In 1984, the population of disabled people 65 or older living in the community for whom there is detailed information comparable to the data available for the 1982 population, is 6,182 (Figure 2, Manton and Liu, 1987).

Longitudinal analyses of the Long Term Care Surveys

Until recently there have been few data bases available that permitted the study of changes in health or patterns of health care use over time. The Medicare History File maintained by the Health Care Financing Administration provides expenditure data and limited demographic information for a sample of beneficiaries over several years and longitudinal data exist for special populations (the Established Populations for Epidemiological Studies of the Elderly, for example). The LTC surveys represent one attempt to remedy the lack of longitudinal data on a nationally representative population, in this instance focusing on elderly people with functional limitations. A wide variety of issues may be addressed with these data, but one that is of considerable interest is factors associated with institutionalization.

One of the great advantages of longitudinal data is it allows one to observe the pathway between a person's state at time 1 (in this case, 1982) and the same person's state at time 2 (1984). Table 2 illustrates this type of analysis. Living arrangements have been thought to be related to likelihood of institutionalization (Branch and Jette, 1982). The LTC surveys indicate over a two year period, 11 percent of elderly people with a functional limitation who lived alone were admitted to an institution, 17 percent among those 85 or older. The percentage institutionalized was higher for those who lived alone than those who lived with a spouse only or with children, but lower than for those living with nonrelatives. A large percentage of those who lived alone in 1982 were still living alone in 1984 (62 percent) even among those 85 or older (50 percent). Those who lived with nonrelatives had the least stable living arrangements. Only a little over a quarter living with nonrelatives in 1982 still did in 1984. A substantial percentage lived alone (32 percent are shown in the table as having made a change in living arrangement other than institutionalization, not shown is that 21 percent changed from living with nonrelatives to living alone). A number of other factors can be examined that may affect likelihood of institutionalization. These include levels of functional ability at time 1 and after institutionalization and use of hospital and Medicare-covered home health services between time 1 and time 2.

There are limitations to the types of longitudinal analyses possible as well, however. First, these data may be best suited for analyzing changes within the functionally limited population. There is little information available about those who were not disabled at time 1 even if they are disabled at time 2 and receive a detailed interview at that time. The 1984 Supplement on Aging (SOA) and the 1986 Longitudinal Study of Aging (LSOA) may provide a better picture of the change from a nondisabled to a disabled state. Second, there is limited information about events between the data collected at time 1 and the data collected at time 2. For example, data are available about who lived with the sample person and the kind of informal care they were receiving at time 1. The Caregiver Survey, conducted only in 1982, also provides some insight about who is providing care and the level of effort involved. If a person is institutionalized at time 2, however, only data concerning functional status, previous nursing home admissions, and who pays for care are available. It may be difficult to determine whether a breakdown in informal caregiving or loss of a spouse as opposed to declining functional status resulted in institutionalization. Inferences can be made based on the level of caregiving required at time 1, but there are no data from time 2 that bear directly on the decision to institutionalize. (A reinterview of caregivers from 1982 or next-of-kin for the institutionalized would have been necessary to obtain such data.) The availiability of continuous data from 1980 to 1985 from the Medicare files on hospital and home health use by the LTC survey populations provide a partial picture of use of formal health services that may relate to likelihood of institutionalization.

Cross-sectional Analyses of the Long Term Care Surveys

The 1982 and 1984 data can be analyzed as separate cross-sectional surveys as well as longitudinally. As a cross-sectional data set the 1984 survey has the advantage of providing data for the entire spectrum of functionally disabled people, those living in the commmunity and those in institutions. (Comparisons are possible between the 1984 institutionalized population and that of the 1985 National Nursing Home Survey. NCHS, Hing, 1987). The 1982 survey contains no data for the institutionalized. It does however provide data on caregivers, as mentioned previously, not available in 1984. Neither survey provides much beyond a few demographic variables on nondisabled elderly people. For this type of information the 1984 Supplement on Aging (SOA) is the more useful data set.

Tables 3 and 4 present comparisons of cross-sectional estimates of the elderly population living in the community with functional limitations. The estimate of elderly people with an ADL living in the community provided from 1982 is 3.9 million people, or 15.3 percent of elderly people living in the community (Table 3). From the 1984 LTC Survey, the estimate is 4.3 million, or 16.4 percent. (These estimates will vary depending on the ADLs included and how a limitation is defined.) The estimate from the 1984 SOA is somewhat higher, reflecting differences in question wording between the surveys as well as the types of activity limitations asked about. By age, the greatest difference in estimates occurs among the younger population. Among those 85 or older the percent with any ADL is similar between the surveys despite the differences in question wording and types of limitations. This suggests there is more convergence between having a problem and needing help with an activity within this age group.

Table 4 presents estimates of selected activity limitations for elderly people living in the community from the LTC Surveys and the SOA. In some instances, such as bathing or using the toilet, the estimates are fairly similar. Estimates between the surveys may be more similar when questions from the SOA reflecting whether people receive help are used.

Tables 3 and 4 illustrate as well the complexities of measuring physical functioning, the need to better understand the measures currently used, and the necessity of improving current measures. Such seemingly straightforward estimates as the percentage of the elderly population with a functional limitation may vary across data sets as indicated here. A difference of a few percentage points could have major implications in terms of the population eligible for services under different long term care policy options.

Summary

The LTC Surveys and the SOA/LSOA represent major data collection efforts undertaken by government agencies to develop the information base for health policy decisions affecting the provision of health services to elderly people. Assuming available funding, there are plans to follow these populations and provide data for a third point in time. These data sets are important for their recognition of the need for detailed information about elderly people and the changes they experience over time. They represent the increased sophistication of both policy makers and researchers in recognizing that aging is a dynamic process. These data sets provide the opportunity to understand that process better as well as the factors that affect the health and well-being of elderly people as they age.

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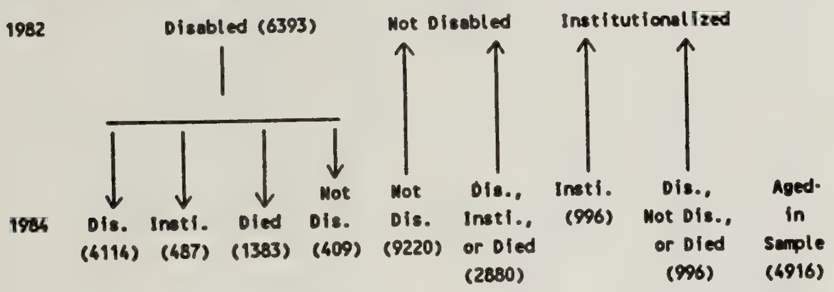
Table 1. 1982/1984 populations*



1982 pop = 6,393
1984 pop = 25,401

*Derived from Manton and Liu, 1987.

Table 2. Living arrangements in 1982 and status in 1984

Living Arrangements In 1982	Status in 1984							
	All elderly people				85 or older			
	Same Living Arrangement	Institutionalized	Died	Different Living Arrangement	Same Living Arrangement	Institutionalized	Died	Different Living Arrangement
	%				%			
Alone	62	11	17	10	50	17	24	9
Spouse only	63	4	20	13	46	10	29	15
With Children	56	7	25	12	53	9	30	8
With Non-relatives	28	15	25	32	28	23	29	20

TABLE 3: Percent of Elderly People Living in the Community With Limitation in Activities of Daily Living (ADLs) by Age

	ALL		AGE		
	# in thousands	percent	65-74	75-84	85+
1982 LTC*(1)	3,910	15.3	9.6	20.1	43.5
1984 LTC*(1)	4,341	16.4	10.0	21.8	47.0
1984 SOA**(2)	5,999	22.7	17.1	27.8	48.8

*Question wording: Do you have any problem...without the help of another person or special equipment?
ADLs = Bathing, Dressing, Eating, Transferring, Getting Around Inside, Getting Around Outside, Using the Toilet, Incontinence

**Question wording: Because of a health or physical problem did you have difficulty...?
ADLs = Bathing, Dressing, Eating, Transferring, Walking, Getting Outside, Using the Toilet

(1) Denominator for 1982 LTC is 1982 US Census Bureau estimates of elderly people excluding institutionalized (1.3% for 65 to 74, 5.8% for 75-84, 21.9% for 85+ and 4.6% overall from NCHS: Hing, 1987) to yield counts of elderly in the community, 25,593,000. Percents will differ slightly if the Medicare-enrolled population is used as a denominator (Macken, 1986). Denominator for 1984 LTC is the final screener cross-sectional weight for persons living in the community, 26,489,000.

(2) From Table 2 in NCHS: Dawson, Hendershot and Fulton, 1987.

TABLE 4: Estimates of Selected ADLs from the SOA and LTC Surveys

	1982 LTC		1984 LTC		1984 SOA		
					Has ADL		Receives help with ADL from person
	#	%	#	%	#	%	%
Bathing	2,148	8.4	2,376	9.0	2,578	9.8	6.0
Dressing	1,002	3.9	972	3.7	1,161	6.2	4.4
Eating	328	1.3	309	1.2	480	1.8	1.1
Transferring*	1,329	5.2	1,383	5.2	2,114	8.0	2.9
Using Toilet	1,069	4.2	1,162	4.4	1,133	4.3	2.3
Walking	-	-	-	-	4,947	18.7	4.8
Getting Outside	-	-	-	-	2,527	9.6	5.5
Getting Around Inside	2,021	7.9	2,135	8.1	-	-	-
Getting Around Outside	3,056	11.9	3,303	12.5	-	-	-

* The LTC Surveys asked about getting in and out of bed. The SOA asked about getting in and out of bed or chairs.

- Not available

SEARCHING FOR TREND SUBSETS IN LONGITUDINAL DATA: THE CASE OF BLOOD PRESSURE IN OLDER PERSONS

Paul E. Leaverton and Eric A. Ross
College of Public Health, University of South Florida

There are several papers at this year's conference dealing with the analysis of data from longitudinal or cohort studies; session A was totally devoted to this topic. Clearly, the National Center for Health Statistics has increasing interest as they become more involved with these kinds of surveys.

In session A, Scott Zeger has elegantly and concisely summarized the rationale and difficulties in creating a framework encompassing all such modeling. One of his practical conclusions, that of relying on the robustness of some of the simpler techniques, is appealing to us. Interpretability, while subjective, is an important attribute to be incorporated into model selection.

There are a variety of statistical models available for the analysis of longitudinal data including differential equations, linear structural equations, "fuzzy sets", and of course, logistic and proportional hazards (Cox) regression. What should be the choice; especially if the results conflict? Epidemiologists have been wrestling with this issue (model choice and its influence on the interpretation of data) with increasing frequency. In the July, 1987, issue of the American Journal of Epidemiology, there is an article entitled "Should We Abandon Statistical Modeling Altogether?" (1). In it, Vandenbroucke reminds us of the purpose of modeling in complex studies and reviews some of the paradoxes that can result.

A researcher would obviously prefer a large sample size so that adequate sub-samples exist for each cross-classification cell of interest. However, with ten variables having only three classes and a minimum of ten observations per cell, we would require a cohort of 600,000 persons. This was pointed out by Truett, Cornfield and Kannel in their classic paper (2) introducing the logistic model to the famous Framingham data set exactly 20 years ago. But, as Vandenbroucke states, "... what does the model perform? The model lays its structure upon the data, i.e., it draws curves of some form through the vast empty spaces in our data, trying to connect some hopelessly distant data points by some smooth curvature." While this description may point out an extreme (all models break down in the extreme), this view is representative of a broader problem. In a more general context, we believe that society has an unfortunate propensity to extrapolate models which have proven successful in one arena to others where they do not apply, or apply poorly. The use of all-encompassing statistical models with blood pressure cohort data may be such a case.

The representativeness of the functional form of models applied to cohort or growth curve data is often suspect but seldom critically examined. The conventional view of aging and physiological function is obtained by plotting and fitting mean values by age, whether cross-sectionally or in a cohort mode. Kidney function, as described by Dr. Besdine in the first plenary session, displays great variation in its rate of decline when individual cohort ("growth") curves are plotted.

This same phenomenon (heterogeneity of change in time) occurs with systolic blood pressure (SBP). The usual view (3) is that SBP rises inexorably with age as shown in Figure one. This is true when one looks at means. However, there is considerable variation in individual blood pressure changes over years, regardless of baseline values. There are many individuals in which blood pressure does not materially increase with age.

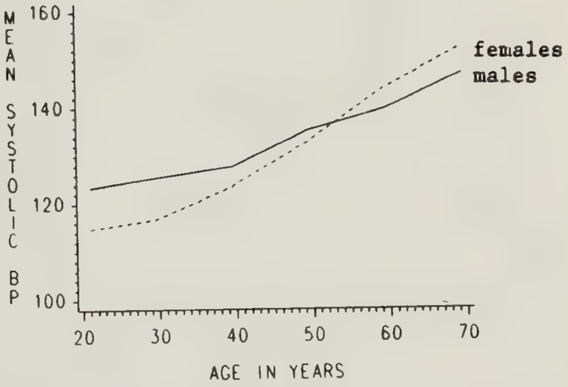


FIGURE 1. Mean systolic blood pressure by age and sex: United States, 1971-1974.

Systolic blood pressure is a crucial variable in health hazard appraisal; it is a consistently strong predictor of stroke and coronary heart disease. And the proportion of persons having high blood pressure does increase with age to a substantial proportion of the population (4). For these reasons it is clearly important to ascertain the modifiable risk factors for this increase. Modeling, using the logistic or proportional hazard approach, has been the standard method to assess risk factors in the development of disease in longitudinal studies. However, such models have difficulties in encompassing all of the complex information and person-to-person heterogeneity in the shapes of the changes over long periods of time. It is of concern that important information may be lost by pushing too hard for everyone in a large study to conform to a given structure. This appears to be the case for creatinine clearance and we are investigating the same phenomenon with longitudinal blood pressure data sets. From examining individual growth curves in several long-term longitudinal studies involving blood pressures, it becomes obvious that the shapes do not fall into a consistent pattern and, therefore, are not able to be parameterized in an easily interpretable single model. It is impossible to identify a typical statistical model which will hold true for all members of the population.

Before utilizing one of the many available simple or complex model possibilities we believe that one should examine individual behaviors. This means calculating every one of the thousands of individual time plots for blood pressure. The statisticians' admonition to "plot the data" is often implemented in simple univariate problems, to see the shape of the underlying distribution. But it is seldom done in regression, for some reason. Of course, until recent years it wasn't practical to construct thousands of time curves to simply look for a common structure or sets of structural forms. But now, with the breakthroughs in computers and computer graphics, this should be equally mandated.

It is our purpose to reexamine major cohort sets to search for subsets of patterns in large long-term cohorts involving blood pressure over time extending into the elderly years and to death. Once appropriate subsets are determined, certain models may be appropriate within each set. Through the support of the National Institute on Aging and the cooperation of the National Heart Lung and Blood Institute and other agencies, we are reexamining several appropriate cohorts utilizing recent computer graphics developments. Preliminary analyses reveal considerable heterogeneity in individual blood pressure changes over twenty years in untreated persons with mid-level blood pressure values.

It is well known that populations exist in the developing world in which mean blood pressure levels do not increase as aging occurs. Stroke rates are correspondingly lower. It is our belief that there are discernible subsets of industrialized populations in which this increase also does not occur. Ideally, these groups would possess differentiable and modifiable risk factors. If the characteristics or risk factors which define these subsets are new, then improved methods of blood pressure control would be implied.

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Session V

Data on the Aged: Plans for the 1990 Census

DATA FOR AN AGING POPULATION

MEASURING THE FUNCTIONAL LIMITATION STATUS OF THE NONINSTITUTIONAL POPULATION

John M. McNeil, Bureau of the Census

Disability is a topic in which there is great interest, but it is also a topic that presents considerable problems to persons responsible for designing the questions that are asked in household surveys.

During the local public meetings that were held as part of the 1990 planning process, state and local government officials consistently listed data on the number and characteristics of persons with a disability as a topic of high priority. A number of Federal agencies have also put disability high on their list of needed data sets. The message that we are receiving as we approach 1990 is similar to the message we received prior to the 1980 census - information on persons with a disability is important to a large number of data users.

This paper describes the efforts the Census Bureau has made to meet user needs. It covers both the 1980 Census - including the attempt to develop and fund a postcensus disability survey - and our 1990 activities. Before we begin to describe those efforts, we will attempt to define some terms and concepts. Our source for this section is a manual published by the World Health Organization called "International Classification of Impairments, Disabilities, and Handicaps."

That manual defines impairments, disabilities, and handicaps in the following way:

> Impairments are concerned with abnormalities of body structure and appearance, and with disturbances of organ or system funtion.
>
> Disabilities reflect the consequences of impairment in terms of functional performance by the individual.
>
> Handicaps are concerned with the disadvantages experienced by an individual as a result of impairments or disabilities.

A look at the exhaustive classification system that is presented in the WHO manual is enough to frighten most persons charged with designing the questions for a disability survey. The manual lists hundreds of categories of impairments, hundreds more of disabilities, and a large number of handicap categories.

We will not discuss the impairment categories here, because our survey efforts have focused on disabilities and handicaps. We have reviewed the classification system for the latter two areas and have selected out our version of the major categories that might be sucessfully identified in a household survey.

Our list of disability categories includes the following:

1. A knowledge acquisition - or learning - disability
2. A listening disability
3. A seeing disability
4. A speaking disability
5. A personal care disability (e.g. bathing or dressing)
6. A walking disability
7. A disability in using various forms of transportation
8. A subsistence disability (e.g. shopping or preparing meals)

Our list of handicaps includes the following:

1. Physical independence handicap (takes into account degree of dependence on aids such as wheelchairs)
2. Mobility handicap (essentially a measure of the ability to go places without the aid of another person)
3. Occupation handicap (the ability to occupy time in the manner customary to the age of the person. For children, the ability to attend regular school; for working-age adults, the ability to work at a job; for all adults, the ability to run a household; for all persons, the ability to take part in recreation)

It is fair to say that most data users would like information on all of the above disabilities and handicaps and on others as well. It is also true that most data users would like information on the conditions that underlie the disability or handicap.

The Bureau of the Census asked a number of questions about disability status in the censuses conducted in the 1800's, but such items disappeared for many decades until reemerging in the 1970 census. In that census, an item was asked about the existence, severity, and duration of a work disability. The question was strongly supported by the Department of Health, Education, and Welfare, and was based on the extensive work disability studies that were carried out at the Social Security Administration (SSA) in the mid-1960's.

The data on disability were widely used but the Census Bureau became concerned about the reliability of the data when a match was carried out between a 1972 SSA disability survey and the 1970 census. It turned out that there was a great deal of inconsistency in 1970 disability status when measured by (a) the 1970 census, and (b) a retrospective question asked in the 1972 SSA survey. From our perspective today, the comparison of the two data sets hardly seems like a fair test of reliability, but the results caused great concern at the time.

The 1980 census effort was marked by an effort to develop a much more comprehensive disability item and by an effort to develop and fund a major postcensus disability survey.

In the National Content Test for 1980, we tested an item that asked about the ability to perform the following activities:

1. Use public transportation
2. Climb stairs
3. Bathe or dress without assistance
4. Do regular school work
5. Work at a job or business
6. Do housework
7. Drive a car

For those of you not familiar with the Census Bureau's National Content Tests, an important part of the test is going back to the original respondents with a reinterview questionnaire. The match between the original interview and the reinterview produces a measure of reliability, and reliability is an important determinant of whether an item is included in the census questionnaire.

The National Content Test disability item would have benefitted a great number of data users, but, unfortunately, the responses to most of the questions lacked reliability.

The reliability problem may have reflected certain basic difficulties persons have in answering disability questions, but it was probably also caused by the questionnaire format. The disability item was in the form of an eight-part question, and the results have convinced us that it is necessary to keep census question designs as simple as possible.

During the 1980 planning period, the Census Bureau became aware that a major offline effort was necessary if we were to produce the very detailed disability data that many users were requesting. We proposed that a survey be conducted after the census to provide detailed data on limitations. The limitations that would be identified would be those described as disabilities and handicaps in the WHO classification system. The survey would also collect data on a range of characteristics that would help describe the situation of persons with disabilities and handicaps. The sample size was to be large enough to provide state-level estimates, and the sample design was to be made very efficient by stratifying on the basis of responses to the 1980 census questions on disability status.

The postcensus disability survey was pretested in Richmond, Virginia in early 1980. The project died soon after, however, because we were unable to come up with the necessary funding. The pretest of the proposed survey was not a waste of time. The effort remains something of a model and the design has been used by the Canadians in their development of a major disability survey and was used in the development of a disability supplement to the Survey of Income and Program Participation. We learned a major lesson from the pretest - when disability surveys are carefully designed, and reinterviews are conducted promptly after the original interview, many disability measures are obtained with a reasonable degree of reliability.

The disability item that actually appeared in the 1980 census included questions on the existence and severity of a work disability and a question on the ability to use public transportation. Again there was widespread use of the data on work disability status but there appeared to be relatively little use of the data on public transportation disability status.

We come now to plans for 1990. Three of the major planning stages for 1990 involved: (1) local public meetings, (2) meetings of interagency working groups, and (3) meetings of the Federal Agency Committee. In each case, the support for disability items was strong. Based on user recommendations, we tested the following items in our National Content Test:

1. Questions about the disability status of children
2. A work disability question
3. A question about the ability to drive a car
4. Questions about the need for assistance
5. Questions about the types of conditions causing limitation
6. Questions about the presence of selected impairments and chronic conditions

The questions about conditions were new for a decennial census planning effort. Such questions have been asked in SSA disability surveys, in the Health Interview Survey sponsored by the National Center for Health Statistics, and they were a part of the questionnaire developed for the pretest of the proposed 1980 postcensus disability survey, but they had never before been seriously considered for inclusion in a decennial census questionnaire.

As before, the major test of content for the 1990 census consisted of the National Content Test including the reinterview. Information on reliability again played a major role in content decisions. The usual summary statistic for measuring reliability is the index of inconsistency. Index values below 20 indicate a high degree of reliability, values 20 to 49 a moderate degree of reliability, and values of 50 or more indicate a high degree of unreliability.

The National Content Test (NCT) data show that responses to disability items had a moderate to high degree of unreliability. For example, there was a low level of agreement between original and reinterview responses to the questions on disability status of children: Four out of the seven questions tested had indexes of inconsistency higher than 50 (this finding is qualified somewhat because few children were identified as disabled). The reliability of responses to questions about work and driving was in the moderate range with index values ranging from the high 20's to the 40's. The NCT questions about the need for assistance produced somewhat conflicting results. A question about whether help was needed to shop, care for the house, or get around outside the home had a moderate degree of reliability (the index ranged from 37 to 51); a question about whether help for bathing, dressing, or getting around inside the home had a poor degree of reliability (index values of 50 or higher). Certain types of conditions and impairments were reported with a reasonable degree of reliability (e.g. diabetes, heart conditions and high blood pressure had index values from 24 to 34), but others had a relatively high level of unreliability (e.g. vision and hearing impairments, and impairments of legs and arms had index values above 50.)

All of the findings on reliability are qualified to some extent because there was a lapse of several months between the time of the original interview and the time of the reinterview.

The Census Bureau's proposal for a disability item considered user needs and data quality and was subject to the constraint that the 1990 questionnaire will have no more space for questions than the 1980 questionnaire. The Bureau's proposal will be submitted to the Office of Management and Budget and to Congress.

The precise wording for the disability item in the dress rehearsal for 1990 that is to be conducted next spring has not yet been determined. Our initial proposal called for a two-part question on work disability and a two-part question on mobility and self-care limitations. The latter questions used the wording:

> Does this person need the help of another person to -
> A. Shop for groceries or get around outside the home?
> B. Take care of personal needs such as bathing, dressing, or getting around inside the home?

A few weeks ago, the Secretary of Transportation asked that we change the wording to identify a larger group of persons with a mobility limitation than those who need the assistance of another person. Since we received that request, we have been in contact with members of the Health and Disability Interagency Working Group and we are examining possible changes that would meet the requirements of the Department of Transportation and do no harm to the interests of other agencies. At present, we are likely to recommend the following wording:

> Because of a health condition that has lasted for 6 or more months, does this person have any difficulty -
> A. Going outside the home alone, for example, to shop or visit a doctor's office?
> B. Taking care of his or her own personal needs such as bathing, dressing, or getting around inside the home?

It seems likely that the 1990 item on disability will provide a much improved data set on the number and characteristics of persons with a disability in states and local areas. The constraints of a decennial census questionnaire means that we will never be able to provide the sort of detail that many users would like. Such detail can only be obtained through the Health Interview Survey (HIS), supplements to the Survey of Income and Program Participation (SIPP), or perhaps, someday, a specially designed large sample disability survey.

The combination of an improved census item and the availability of detailed national data from HIS and SIPP means that policy makers and planners should have better data in the 1990's than they have had in the past.

1990 CENSUS PLANS FOR ENUMERATION OF PERSONS LIVING OUTSIDE OF HOUSEHOLDS: PERSONS IN INSTITUTIONS, IN COMMUNITY RESIDENTIAL BOARD-AND-CARE HOMES, AND THE HOMELESS

Arnold A. Goldstein, Denise I. Smith, and Cynthia M. Taeuber
Bureau of the Census

Introduction

During the 1980's, institutions and other nonhousehold living arrangements have been the focus of a great deal of attention. Journalists, researchers, those in the medical professions, sociologists and gerontologists, and the public at large have become more concerned with the conditions under which the institutional and homeless populations are living. The many stories in the mass media about conditions in nursing homes, overcrowding in prisons, and the plight of the homeless are examples of a rising national interest in these issues. A less popularly recognized phenomenon, but numerically important nevertheless, is the trend toward deinstitutionalization of persons with mental retardation or developmental disabilities.

The Census Bureau has enumerated in decennial censuses the institutional population and others living outside of households since 1850. As with many aspects of our national life, when new issues arise census procedures change to ensure continued relevance of the data. In this paper we describe plans to enumerate the nonhousehold population in the 1990 census. We highlight changes and new procedures under consideration, even though all plans are not final.

Many people outside the Census Bureau have been consulted as we have formulated plans for the 1990 census. Comments from data users offered in public meetings around the country and dialogues with officials from all levels of government contribute to the planning process. Through the various modifications we hope to reduce misclassifications, elicit a higher response rate, and provide more useful tabulations.

In the sections that follow, we outline current planning for enumerating persons in institutions and other group quarters, in community residential "board-and-care homes," and the homeless population.

Group Quarters: Institutions and Other Group Living Arrangements

For purposes of enumeration and tabulation, the Census Bureau classifies all persons as living in either housing units or group quarters. Housing units include homes, apartments, and mobile homes, as well as less traditional forms of residence such as boats, cars, and tents. Group quarters include institutions and a variety of noninstitutional living arrangements.

Institutions are living quarters that provide some kind of formal care or custody regardless of the number of people residing in them. In 1990, institutions will be defined as living quarters occupied by one or more persons under formally authorized, supervised care or custody, regardless of the availability of nursing or medical care or the length of stay. Generally, institutionalized persons are restricted to the institutional buildings and grounds and have limited interaction with the surrounding community. Aside from such obvious examples as hospitals, homes for the aged, and prisons, institutions also include orphanages and halfway houses operated for correctional purposes.

Noninstitutional group quarters, often identified as "other group quarters" in census tabulations, are usually group living arrangements in which no formal care or custody is provided. Some of these are classified as group quarters only if ten or more unrelated persons live in them. Some examples are rooming and boarding houses, college quarters off campus, convents, monasteries, maternity homes, community-based group homes for the mentally or physically handicapped, drug or alcohol abuse halfway houses, homes for battered women, and other group homes such as communes.

Other types of living arrangements are classified as noninstitutional group quarters regardless of the number of residents. These include dormitories for agricultural or other types of workers, college dormitories, fraternity and sorority houses, military quarters, and quarters for staff members of institutions. Emergency facilities to shelter homeless individuals and families on a temporary basis also fall under this category if those facilities provide for sleeping. Thus, emergency housing, missions, flophouses, Salvation Army shelters, hotels and motels used entirely for homeless persons, and group homes for runaway, neglected, and abused children will be counted as noninstitutional group quarters.

Researchers planning to compare 1990 census data to those from earlier censuses will be interested in the classification changes from 1980 that are planned for specific types of group quarters. The criteria for what constitutes care of residents, part of the definition of an institution, will be more stringent than for the 1980 census. For the 1990 census, "care" means organized medical or formally authorized custodial care. This tightening of the definition of care will cause maternity homes to be reclassified from "institutional" to "noninstitutional." Halfway houses of correctional institutions and hospital wards for patients who have no usual home elsewhere will be changed from "noninstitutional" to "institutional." These changes are not expected to affect greatly the overall comparability of the data with earlier censuses.

Enumeration of group quarters will begin the day following 1990 census day and will last about 2 weeks. To collect information on persons living in group quarters, enumerators will visit each group quarters, list the names of people staying there, and will usually leave Individual Census Reports (ICRs), nearly identical to regular census questionnaires, for residents to complete. The enumerator will return a day or two later to retrieve the forms and conduct personal interviews if necessary. (In some hospitals and prisons, the staff of the institution may request that information be gathered from administrative records if the presence of a census enumerator would have a disrupting effect on operations at the facility, or if the enumerator might be endangered.)

Identification of Community Residential Board-and-Care Homes

The 1985 National Nursing Home Survey, conducted by the National Center for Health Statistics, determined that about 5 percent of the population aged 65 and over reside in nursing homes on any given day. Some elderly who need less care may live in a noninstitutional, residential environment where such care is provided for a fee. This latter type of arrangement is termed a "board-and-care home."

In the census, facilities for 10 or more persons are already separately identified as group quarters. The census also separately tabulates housing units with nonrelatives, but not the reason for their presence. That is, we have never tried to separately identify housing units that are used for social service purposes, such as board and care services for persons with physical disabilities, the mentally retarded, the mentally ill, and the elderly.

With continuing deinstitutionalization, increasing life expectancy of the developmentally disabled, and an increasingly large population aged 75 and over, it is believed that the number of board-and-care housing units is growing, but the extent is unknown. Estimates for 1990 range from 100,000 to 1,000,000 such homes of all sizes (including group quarters with 10 or more people but no nursing care).

As a result of the recommendations of a Federal Interagency Work Group, a short and long (3-part) version of a question on board-and-care was tested in the 1986 National Content Test for the decennial census. Results were difficult to interpret because of the low response rate and the small number of such units. We did determine that the short version of the question was unacceptable in terms of data quality. But aside from considerations of data quality, a question that applies to less than 500,000 housing units would unreasonably increase respondent burden for the 100 million households that will be answering census questions in 1990. Thus, the board-and-care question was not included in the proposed list of 1990 census questions.

The Census Bureau is now exploring the possibility of a post-census survey of households with 2 or more nonrelatives and of group quarters for the elderly, mentally ill, and mentally retarded. Enumerators would ask questions similar to those on the National Content Test to determine whether residential care is being provided to the nonrelatives. The conduct of such a survey will depend largely on the availability of funding from the other Federal agencies who need the data.

Enumeration of the Homeless Population

In response to increasing national concern for the homeless, the Census Bureau plans to provide a count and limited characteristics for this population in the 1990 census. The homeless population is found in a variety of living arrangements and there is no generally agreed-upon operational definition of homelessness. Is one homeless only if one lacks a roof over one's head? Or should those in emergency shelters be included as well? Some advocates would widen the definition to include the "potentially homeless," that is, those at risk of becoming homeless for various reasons, such as battered women and doubled-up families.

The 1980 census included counts of persons aged 15 and over who were living in emergency shelters. The shelter was counted as their place of residence, however, only if they could provide no other address. Apparently the sheltered population was much smaller than at present and many sheltered persons did give another address, as the national count for the sheltered population was only about 28,000. Another 1980 census operation, aptly named "casual count," was conducted several months after the census. Enumerators in selected large central cities asked people they encountered in the street if they had been counted in the census. If they said they had not, they were asked if they had a usual home elsewhere. Those who had no usual home elsewhere were included in the casual count, which added about 23,000 people to the population. Together, these 51,000 people could not be said to constitute a reasonable estimate of the number of homeless in 1980, however. Many of those in shelters or in the casual count were excluded from these numbers because they responded that they had another home elsewhere. Further, there was no attempt to conduct a nationwide count of the "street population."

Presently there is no widely accepted national estimate of the homeless population. The U.S. Department of Housing and Urban Development used six different methodologies to arrive at estimates of 250,000 to 300,000 homeless in the early 1980's. Some advocates for the homeless claim that there are 2 million to 3 million, but their methodology and definitions are unclear. The Census Bureau has no official opinion or estimate of the actual number of homeless, but through the 1990 census we hope to provide better information upon which estimates can be based.

To provide data on the homeless population in the 1990 census, we have confronted three major issues. First is the lack of a generally accepted definition on what groups constitute "the homeless" population. The Census Bureau will not provide a tabulation labelled "homeless." Rather, the 1990 census will tabulate various components. Data users can combine components to satisfy their view of what the definition should be. For example, we will provide separate tabulations of the population in shelters, the population counted on the street, the population in shelters for battered women, and households with multiple families. Data users will be able to add up the components they judge most appropriate.

A second issue in enumerating the homeless is the rule we use for determining the appropriate residence where they should be counted. In 1980, they were asked if they had a usual residence elsewhere, and, if they indicated they had a usual home elsewhere they were counted at that other residence. In the 1990 census, we will assume their usual residence is where they are found and that is where they will be officially counted. This will make it possible to enumerate and publish data for the sheltered and the street populations as whole groups.

A third element in 1990 census planning for enumeration of the homeless population is to devise enumeration procedures. While none of the procedures is final, planning is proceeding along the following lines.

The enumeration procedures will be conducted nationwide, and will include persons of all ages rather than only persons aged 15 and over, as was the 1980 procedure. The census district offices will work with local areas to predesignate all shelters and street locations (including noncommercial campsites and similar living situations in rural areas) where the homeless population is found. Because the budget for conducting the census is finite, criteria will be developed to establish priorities for the places that will be designated for enumeration.

A special operation for this enumeration will be conducted probably in the middle of the week, in the middle of March 1990. The enumeration will be carried out at night, when this highly mobile population will be as stable as it ever is. In many shelters, the population is "locked in" after a certain hour, so we will enumerate the sheltered population as they enter the shelters for the night. Persons in shelters will be sampled and asked the long-form questions just as with the the rest of the group quarters population.

The street population will be counted

generally from midnight until daybreak. Sleeping persons will not be awakened; rather, enumerators will make their best estimate of the person's age, race, and sex. Tabulations will be limited to 3 or 4 broad age groups. Enumerators, working in teams, will interview persons who are awake and will ask only the short-form basic demographic questions. We will not attempt to conduct the longer interviews required to ask social and economic questions. Enumeration of the street population will be a particularly challenging assignment, and it is the first time we have approached the problem in this way on a nationwide scale.

Coverage of as many persons as possible by the census is a major concern in the enumeration of persons living in streets and open areas. Many in these populations may not want to be found or counted, and since we do not live in a coercive society, those who are determined to remain out of the census count will manage to do so. It will not be feasible to search every block in the country. We are still discussing whether enumerators will count only persons who are out in the open or whether they will search for the many persons who sleep concealed for their safety. Studies of the homeless have found that women and children seem to be particularly adept at finding good hiding places. Enumerators have never been required to enter abandoned buildings and especially not in the middle of the night, due to the obvious dangers involved. Enumerators will work in teams and the Census Bureau is considering other measures to improve safety. Police escorts, however, will not be used because their presence would reduce appreciably the willingness of people living in homeless conditions to be counted.

Conclusion

The Census Bureau must continually change its products and data collection methods to keep up with a Nation in flux. To maintain its relevance as a source of reliable information on which to base informed debate on issues of national significance, the Census Bureau is attempting to meet the challenges of counting the nonhousehold population, within the constraints of the budget and current knowledge. We welcome any comments or suggestions our readers may have.

1990 CENSUS PLANS FOR DATA PRODUCTS AND ALTERNATIVES FOR PROVIDING DATA ON THE OLDER POPULATION

Patricia A. Berman, Census Bureau

INTRODUCTION

During our consultations with data users about their needs from the 1990 census, it was clear that information on the older population was one of the fastest growing data needs for the 1990s. Although an extensive amount of information was published from the 1980 census in printed reports and computer files, it was not enough. Users wanted more data and earlier. The number of data users increased as well. Given the numerous uses of the data by various segments of the user community--policy makers, planners, academicians, the business community and others--it was clear that the Bureau of the Census must revise the sequence and type of data published on the older population from the 1990 census. To do this will require including data on the older population in the early reports and computer files as well as producing special data products.

Currently, the Bureau of the Census is developing its final plans for the data products to be included in the 1990 Tabulation and Publication Program and starting to work on the overall design of the tabular presentation for geographic areas and subgroups of the population--the older population, racial groups, and Hispanic subgroups. This paper provides various alternatives for providing data on the older population. The alternatives are presented to solicit ideas on the tabular presentation before we begin to develop the table outlines for the publications and the tally matrices for the computer files.

In addition to the standard data products, we can produce special reports or computer tape files to meet unique or specialized data needs for selected subjects such as income and employment as well as for subgroups of the population. These products are usually prepared during the latter part of the tabulation and publication cycle. We also want your ideas on alternatives for these products.

GENERAL DESIGN OF THE 1990 CENSUS TABULATION AND PUBLICATION PROGRAM

The overall design of the 1990 Tabulation and Publication Program will be similar in data content and geographic coverage to the 1980 census. We plan, however, to produce the data products on an accelerated schedule. Also, the data products will, in many cases, be issued in a different sequence and possibly in additional formats to provide the earliest possible release of a wide range of data. Although we expect that the traditional media forms--printed reports, computer tapes, and microfiche--will provide the largest amount of 1990 census data to users, newer types of media may be used on a limited basis for 1990. The newer media--laser disks, flexible diskette for microcomputers, and on line information systems--are likely to be available to users after the data products have been released in the more traditional forms. Depending on the results of the 1990 program, we may expand their use for the 2000 census.

Our first products, of course, will be those needed to fulfill our legal requirements for Congressional reapportionment and state legislative redistricting. Beginning in mid-1991, we will issue the 100-percent products that will show the basic demographic and housing characteristics for blocks, block groups, census tracts, places, minor civil divisions, counties, American Indian areas such as reservations, statistical areas such as metropolitan statistical areas, states, and the Nation. In late 1991 or early 1992, we will begin to issue the products based on sample data which include social, economic, and detailed housing information for most of these same geographic areas. All standard census products are scheduled for release by late 1993.

In addition, we plan to produce special reports and computer files, special tabulations, as well as provide data through a new program for 1990--User Defined Areas. These products are designed to meet special or unique data needs--tabulations for geographic areas not defined in census publications, specialized tabulation universes, and so forth. Some special products like special tabulations and user defined areas will be prepared on a cost-reimbursable basis.

ALTERNATIVES FOR PROVIDING DATA ON THE OLDER POPULATION IN EARLY DATA PRODUCTS

Demographic and General Housing Characteristics

The early products such as the 1980 General Population Characteristics and General Housing Characteristics are based on data collected from the census questions that are asked of all persons--sometimes referred to as the "short-form" or the "100-percent" questionnaire. The following has been proposed for 1990--the content is very similar to what was asked in the 1980 census--

POPULATION

Household Relationship
Sex
Age
Race
Marital Status
Hispanic origin

HOUSING

Number of units in structure
Number of rooms in unit
Tenure--owned or rented, condominium
Value of home or monthly rent
Vacancy Characteristics
Plumbing
Telephone
Meals in rent

Given that the subject matter is limited, we could provide an extensive amount of age detail on the computer files and expand the amount of data in printed publications. Summary tape files are designed to provide statistics with greater subject and geographic detail than is feasible or desirable to provide in printed reports.

Table A, "Age of the Population by Sex: 1990," and Table B, "General Characteristics of the Population by Age and Sex: 1990," are hypothetical examples of the kinds of data that could be produced from the 1990 census. These data can easily be carried on the computer files for all the geographic areas shown in tabulations such as states, counties, places, and so forth. We could also show these data for the United States and states in publications. Similar kinds of data by age of householder would be published showing the housing characteristics. Although we have not developed the tabular presentation for racial and Hispanic origin groups, we can assume that most of these data would also be available by race and Hispanic origin in both publications and computer files.

When we show data for smaller places like counties and census tracts in printed reports, we will not be able to publish the same amount of detail shown in Tables A and B. We will either eliminate some of the age detail or the subject detail or a combination of both. Table C, "General Characteristics of the Population by Age," shows examples of alternative presentations that could be used in printed reports.

Questions:

1. Is the age detail shown in Table A the amount of information that is needed?

2. Does the amount of subject and age detail shown in Table B meet most of your data needs?

3. Since we will have to cut back on the amount of detail shown in Table B for the substate areas in publications, what do you recommend? Should we cut back on the age detail? Subject detail? A combination of both alternatives?

Social, Economic, and Detailed Housing Characteristics

These data products, similar to the 1980 General Social and Economic Characteristics and Detailed Housing Characteristics are based on sample tabulations--questions asked of only a portion of the population and sometimes referred to as the "long-form" or the "sample" questionnaire. The subjects proposed for 1990 are similar to 1980; they are--

Population

Social characteristics:
  Education--enrollment and attainment
  Place of birth, citizenship, and year of entry
  Ancestry
  Language spoken at home
  Migration
  Disability
  Fertility
  Veteran status

Economic characteristics:
  Employment and unemployment
  Occupation, industry, and class of worker
  Place of work and commuting to work
  Work experience and income in 1989

Housing

Heating equipment and fuels
Source of water and method of sewage disposal
Autos, light trucks, and vans
Kitchen facilities
Year structure built
Year moved into residence
Number of bedrooms
Farm residence
Housing quality
Shelter costs, including utilities

Table A.--Age of the Population by Sex: 1990

United States	United States	Alabama	Alaska	Arizona	...	Wyoming
TOTAL						
All persons......						
Under 5 years......						
5 to 9 years.......						
10 to 14 years.....						
15 to 19 years.....						
20 to 24 years.....						
25 to 29 years.....						
30 to 34 years.....						
35 to 39 years.....						
40 to 44 years.....						
45 to 49 years.....						
50 to 54 years.....						
55 to 59 years.....						
60 to 64 years.....						
65 to 69 years.....						
70 to 74 years.....						
75 to 79 years.....						
80 to 84 years.....						
85 to 89 years.....						
90 years and over..						
Median age.........						
16 years and over..						
18 years and over..						
60 years and over..						
65 years and over..						
75 years and over..						
85 years and over..						

Repeat "TOTAL" for:

MALE
FEMALE

Table B.--General Characteristics of the Population by Age and Sex: 1990

United States	All persons	18 to 25 years	25 to 34	35 to 44	45 to 54	55 to 64	65 to 69	70 to 74	75 to 79	80 to 84	85 to 89	90 years and over
TOTAL												
Relationship												
All persons...................												
Persons in households.......												
Householder....................												
Living alone..................												
Living with other relatives...												
Living with spouse..........												
Living with nonrelatives......												
Spouse.........................												
Other relatives................												
Brother or sister.............												
Father or mother..............												
All other relatives...........												
Nonrelatives...................												
Unmarried partner.............												
Housemate or roommate.........												
All other nonrelatives........												
Persons in group quarters...												
In institutions................												
In other group quarters.........												
Marital Status												
Persons, 15 years and over....												
Single..........................												
Now married, except separated...												
Separated.......................												
Widowed.........................												
Divorced........................												

Repeat "TOTAL" for:

MALE
FEMALE

Table C--Alternative #1

Table C.--General Characteristics of the Population by Age: 1990

Counties	County A	County B	County C	. . .	County Z
PERSONS 55 to 64 YEARS OLD					
Relationship					
Persons, 55 to 64 years old....................					
Persons in households........					
Householder.....................					
Living alone..................					
Living with other relatives...					
Living with spouse..........					
Living with nonrelatives......					
Spouse..........................					
Other relatives................					
Nonrelatives....................					
Persons in group quarters....					
In institutions.................					
In other group quarters.........					
Marital Status					
Persons, 55 to 64 years and over....................					
Single..........................					
Now married, except separated...					
Separated.......................					
Widowed.........................					
Divorced.......................					

Repeat "PERSONS 55 TO 64 YEARS OLD" for:

PERSONS 65 TO 74 YEARS OLD
PERSONS 75 YEARS OLD AND OVER

Table C--Alternative #2

Table C.--General Characteristics of the Population by Age: 1990

Counties	County A	County B	County C	. . .	County Z
RELATIONSHIP					
Persons under 35 years old...					
In households.............					
Householder....................					
Living alone.................					
Living with other relatives...					
Living with nonrelatives......					
Spouse.........................					
Other relatives................					
Nonrelatives...................					
In group quarters...........					

Repeat "RELATIONSHIP" for:

Persons 35 to 54 years old
Persons 55 to 64 years old
Persons 65 to 74 years old
Persons 75 years old and over

Counties	County A	County B	County C	. . .	County Z
MARITAL STATUS					
Persons under 35 years old...					
Single........................					
Now married, except separated..					
Separated.....................					
Widowed........................					
Divorced......................					

Repeat "MARITAL STATUS" for:

Persons 35 to 54 years old
Persons 55 to 64 years old
Persons 65 to 74 years old
Persons 75 years old and over

Given that many more subjects are included in sample tabulations and most of the data will also be cross classified by race and Hispanic origin, it will be necessary to limit the amount of data in both printed reports and on computer files.

Questions:

1. Which subjects are most important for the older population?
2. How much age detail is needed in these tabulations?
3. Are cross tabulations of both age and sex required for each subject area?

ALTERNATIVES FOR PROVIDING SPECIAL DATA PRODUCTS ON THE OLDER POPULATION

There are a number of special products being considered for the older population. Given our limited resources, we will choose some but not all from the following list of alternatives--

1. Public Use Microdata Sample--Public-use microdata samples are computerized files containing most population and housing characteristics from a sample of the individual census records. These files contain no names or addresses, and geographic identification is sufficiently broad to protect confidentiality.

   We are discussing the feasibility of producing such a file for the older population so cross tabulations of social and economic characteristics with age detail are possible. There are some confidentiality issues that must be resolved as well as cost considerations. Data could be included on the tape for states and substate areas with 100,000 or more older persons. Although the amount of geography is limited, such files allow users to prepare customized tabulations.

   Questions:

   Would such a file be useful?

   What kinds of geography are most needed? States? Large Metropolitan Areas? Large Counties?

2. Special Computer Summary Tape File--On this file, we could provide very detailed cross tabulations as well as focus in on specific issues. For example, all cross tabulations of social and economic characteristics could be tabulated by income, disability, and so forth. Another possibility is to show extensive tabulations by age by whether persons are living in a household or in a group quarters by type of quarters (for example, nursing homes).

   Questions:

   Would this type of summary file be more useful than a microdata sample file?

   Are there any special cross tabulations that should be made?

   What are the most important subjects? What detail is needed?

   What age distributions are needed? Single years of age?

   What geography is needed?

3. The final alternative is a special publication or subject report that would focus on special issues of the older population or provide more age detail (for example, single years of age).

   Questions:

   Would this meet the major needs?

   Are the same kinds of information needed in this report as the special summary computer files?

   Would a combination of Alternatives 2 and 3 meet most data users needs at both the national and local levels for research as well as policy making?

1990 CENSUS PLANS FOR DATA PRODUCTS AND ALTERNATIVES FOR PROVIDING DATA ON THE OLDER POPULATION

Patricia A. Berman, Census Bureau

OTHER ALTERNATIVES FOR OBTAINING DATA ON THE OLDER POPULATION

In addition to the standard and special products produced by the Bureau of the Census, we also are planning to offer two other vehicles to obtain data--Special Tabulation and User Defined Areas Programs. Both programs would be offered on a cost-reimbursable basis.

Special Tabulations allow users to define the types of subject detail for tabulation, the dissemination media (tapes, microfiche, and so forth) and the geographic detail. User defined areas will include a standard set of tables, including a variety of subjects, but users can define the geographic areas for tabulations. Since the subject detail and dissemination media are standard, the program has the capacity to produce the requested data faster and at less expense than a special tabulation. The tables for this program have not been designed as yet but we will use comments from our data users to determine their final content. Since these tables will be designed to meet a variety of user needs, we do not expect to be able to accommodate extensive age detail. For example, age distributions could be shown for 5 year age groups but not for single years of age.

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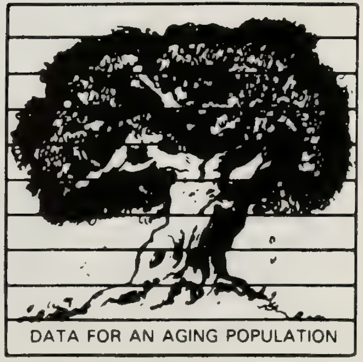
Session W

Panel on Issues of Morbidity and Mortality in the Oldest Old



DATA FOR AN AGING POPULATION

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CHANGING HOSPITALIZATION PATTERNS FOR THE OLDEST OLD: IMPLICATIONS FOR HEALTH POLICY

E. Greer Gay and Jennie J. Kronenfeld
University of Wisconsin-Milwaukee and University of South Carolina

ABSTRACT: A study of 227,771 discharge abstracts from 68 of the 71 South Carolina shortterm, acute care hospitals compares changes in the inpatient market available to the oldest old Medicare patients (85 and older) with those less than 70 and those 70-84 between 1981, the last year when all hospitals were under costbased reimbursement, and 1984, the first year in which all hospitals were under DRGs. All three populations experienced changes; however, inpatient services were reduced the most for the oldest old population.

INTRODUCTION: In an effort to address cost containment in Medicare expenditures for hospitalization, Congress enacted the 1983 Social Security Amendment, which ended a cost-based system of reimbursement for inpatient care and instituted a prospectively paid system that effectively placed hospitals at risk for inefficient use of resources in the provision of inpatient care. Ostensibly regulation of an industry becomes necessary when evidence of either demand or supply inefficiencies in the market place occur; when government costs become too high; or when access problems exist (Feldstein, 1983). DRGs attempt to control perceived Medicare market inefficiencies by enacting expenditure limits to control supply, and utilization review through Professional Review Organizations (PRO) to address demand inefficiencies. Cook, Shortell, Conrad, and Morrisey (1983) propose a theory to predict hospital response to regulation that financially constrains the environment. This theory argues that regulation serves as a "tax" on an organization's behavior. DRGs meet the criteria, established by Cook and associates, to serve as a stringent "tax" on output; therefore, according to the theory, hospitals, as organizations, should seek ways to decrease the use of the affected resource or service in order to survive the economically stringent environment imposed by the regulation. The purpose of this research is to explore the impact of DRGs on hospital behavior and its effect on the elderly who must seek care in the more financially constrained environment, created through this legislation.

DRG STUDIES: National studies of the impact of DRGs have found the implementation of both practice and product changes. DesHarnais and colleagues (1986) observed decreases in LOS in all regions of the country. Shifts among certain DRGs occurred. Nonspecific DRGs showed a large drop in admissions. Shifts to higher paying DRGs were observed. Admissions for new procedures, such as major joint procedures and removal of coronary artery obstruction demonstrated "dramatic" increases in admissions. Other increased admissions were those for chemotherapy and complications of treatments. Fewer admissions were observed. Chesney and Long (1986) also demonstrated dramatic changes in hospital product lines (i.e., output based on discharge location) since the implementation of DRGs. Fewer Medicare admissions returned home without a need for further care (by definition, a completed product). Far more were discharged to home health services and other longterm care facilities. Vladeck (1985) warned that incentives in DRGs encourage a system that could in effect underserve the population.

QUALITY OF CARE ISSUES: In a concern to monitor quality changes with the implementation of DRGs, the Health Care Financing Administration (HCFA) awarded RAND corporation a $2.9 million contract to compare pre and post-PPS data. In an early report of presenting the research agenda Lohr and colleauges (1985) proposed that the prospective payment system (PPS) implemented in the Social Security Amendments for reimbursement of hospital care for Medicare clients (DRGs) could promote either positive or negative effects on quality of care. They predicted shifts in inpatient care to an outpatient basis and earlier discharges from hospitals, both of which could be positive; however, the potential exists for underproviding certain types of services, premature discharges which may lead to readmissions, and unnecessary admissions of profitable patients. Using trend analysis from 1980 to 1983, DesHarnais and associates (1986) observed no evidence of a deterioration in quality of care provided Medicare patients in 1984. They reported a decrease in hospital utilization, but for those admitted consultation rates remained constant, inhospital deaths and readmission were unchanged from previous trends.

METHODOLOGY: Medicare discharge summaries (n=227,771) from all reporting South Carolina, short term, nonfederal, acute care hospitals, for the years 1981 and 1984 (n=68) were used to compare hospital responses to the implementation of DRGs. Discharges from three hospitals not included were a 16 bed nonreporting hospital, a hospital serving a mixture of alcohol/drug treatment and acute care patients, and one hospital in HSA V which shares its market with Georgia. The year 1981 demonstrated activity under costbased reimbursement. The year 1984 was chosen because it was the first year available in which all hospitals were under DRGs.

The Medicare Case Mix (MCM) and a modified version of the Laspeyres type scalar mix index (described by Rafferty, 1975), the Length-of-Stay Case Mix Index (LOSCMI), were used to measure hospital activity in the Medicare inpatient market before and after the implementation of DRGs. The MCM used weights mandated under Medicare's reimbursement system; the LOSCMI used weights calculated from South Carolina specific Medicare patient practice prior to the implementation of DRGs.

Case mix comparisons were made for each of three age groups: below 70 (the age break in reimbursement for many pairs of DRGs; payment is lower for this age group unless there is a comorbidity or complication); 70-84; and 85 and older (to assess the impact of DRGs on the frail elderly, generally that portion of the Medicare population that is more infirmed and thus a poorer financial risk). These measures were used to see if hospital activity changed with regard to age. Case mixes were calculated as follows:

$$MCM_h = \quad P_j * W_j \ ;$$

where the hospital's proportion of patients in a given DRG (P_j) is multiplied by the normalized cost weights (W_j).

$$LOSCMI_h = \frac{S_{0j}(n_{1j}/N_1)}{S_{0j}(n_{0j}/N_0)} \ ;$$

where S_{0j} = average LOS for patients of DRG_j during base period; $n^1{}_j/N_1$ = the proportion of patients of case $type_j$ during the time after introduction of legislation; and n_{0j}/N_0 = the proportion of patients of case $type_j$ during the time period prior to the new legislation.

Profit margin comparisons were determined for each of the three age groups. It is argued that profit margin can be defined as the percent difference between the MCM, a reimbursement driven measure, and the LOSCMI, a state-specific practice driven measure. Because of the way DRG weights were derived, these two values should be close. If MCM is higher than LOSCMI then a profit can be anticipated; if lower, a loss.

Comparisons in practice and product changes were made between age groups and for selected DRGs. Of interest was the effect of DRGs on services provided the Medicare client once admitted to the hospital and did that practice vary according to age groups.

FINDINGS

CHANGING ADMISSION PATTERNS: Because of the potential for hospital-assumed risk, DRGs foster a perception of an economically constrained environment. The law does not define who must be admitted; only how much, or even if, that admission will be paid for. At risk for admissions should be the oldest old, for whom reimbursement might not exceed marginal costs because of the potential for this cohort to be more severely ill and command more resources than the average reimbursement accorded a particular DRG, and the young-old, for whom outpatient treatment, especially surgical procedures, would be feasible, thus making their inpatient hospitalization a target for denial of reimbursement (South Carolina had one of the first Peer Review Organizations (PRO) in the US and one of the toughest in light of decreasing inpatient surgeries; Hospital Week, July, 1984). The number of admissions for the oldest-old (85 and older) increased only slightly (from 9.2% to 9.9%), but not as much as that for the 70-84 population group (49.2% to 53.3%). Admissions for the young old (69 and under) decreased (41.6% to 36.8%). Obviously, the PRO's influence was felt by 1984. Increasing admissions would remain a financial incentive only for those DRGs for which reimbursement exceeds marginal costs and for which payment would not be denied.

By changing admitting practices hospitals have found they can influence resource consumption. Table 1 presents these changes. Hospitals increased admissions from outpatient clinics for all age groups. By expanding outpatient settings, hospitals could do preadmission testing, collect a fee-for-service payment on the initial laboratory or x-ray procedures, and decrease the amount of resources used in the inpatient service site. This same practice is possible and probably happened to those clients admitted through the emergency room; yet admissions from this area decreased for all age groups, but slightly more so for those 70 and older. This may represent better screening practices to prevent inappropriate admissions who may have been denied reimbursement (Under the former system, a hospital could usually recoup cost for an admission for observation).

The decrease in admissions from long-term care facilities (LTCF) may become an issue on access for the frail elderly. Determining the cause for the decrease is not clear. It may be due to an 'increasingly expressed unwillingness on the part of the nursing home industry to release a bed to be filled by a hospital discharge, potentially a sicker client than the one for whom the bed was released. Therefore, only the sickest of clients are sent to the hospital. Since the demand for nursing home beds far exceeds the supply in South Carolina due to a legislated freeze on Medicaid nursing home beds, the industry effectively controls this market. Another plausible explanation could have been that hospital emergency rooms, in an effort to better screen admissions, have treated and released those who could be managed in the LTCF.

Noteworthy, and certainly a policy concern if not an issue, were the increases in readmissions for all age groups. Trim points in reimbursement based on LOS can result in premature discharges, which can lead to readmissions. This is costly to all parties involved (the elderly, for often readmission can mean increased physical and emotional debilitation; and the hospital for whom reimbursement will be denied if the client is readmitted within 15 days currently).

CHANGING DEMOGRAPHICS: The average age of the Medicare inpatient client increased by almost two years with the implementation of DRGs as the young-old cohort experienced declining hospitalization rates. (See Table 2.) Other pertinent demographic variables that may be important to consider, given DRG incentives to decrease LOS, are sex and race. More males or whites admitted could mean shorter stays. Overall, the percent nonwhite admissions remained unchanged; however, when considered by age group there were slight declines in the nonwhite young-old and old-old groups. There was a slightly larger increase in males admitted in the young-old than in the other age groups although each cohort experienced small increases in male admissions. The importance of this change lies in the potential direction that the market may take. If this were to represent a trend, then the possibility exists for access problems for inpatient hospitalization of the nonwhite and the female within the youngand old-old cohort.

The 1984 Medicare client was sicker. All measures of case mix increased significantly ($p < 0.0001$) for all age groups. Profit potential grew for all age groups; however, the margin for the old-old remained the smallest. The largest profit potential lay with the young-old cohort. This may explain the retrenchment in services and service markets available to the old-old that occurred with DRG implementation as hospitals sought survival within Medicare's imposed prospective reimbursement system.

PRACTICE CHANGES: Table 3 presents practice changes by age groups and demonstrates a potentially negative finding for quality of care provided within the old-old service market. This group experienced the greatest decrease in LOS (18%), followed by the 70-84 (13.5%) even though the MCM and LOSCMI had increased significantly suggesting a need to increase time within the hospital (NOTE: For all three groups, the percent dying remained about the same or, for the oldest old, decreased slightly, so that dying did not artificially reduce LOS). The young-old experienced a decline of only 5.7 percent.

Early discharge is not necessarily evidence for deterioration in quality of care provided. Yet, this cohort experienced a decline in the numbers of procedures administered to them even though this cohort was sicker; i.e., a higher case mix and more diagnoses than any other age. Medical practice change cannot explain away this decrease, given the experience observed in the market by the other two cohorts. During this time period, the 70-84 year old was able to receive the same number of procedures, on average, as was available to this participant in 1981. This may, in fact, represent some retrenchment in services for this age group since they were sicker in 1984 than in 1981. The young-old saw an increasing number of procedures available to a participant from this cohort. Given the increase in the severity of this cohort, an increase in procedures would seem appropriate and lend even more credence to demonstrate that medical practice had not changed. Rather, fewer procedures available to the old-old suggest a reaction to the profit margin and the creation of a pattern of practice that is reimbursement driven. Fewer procedures would suggest an attempt on the part of the hospitals to stabilize and discharge the old-old cohort as quickly as possible, a conclusion reached by Meiners and Coffey (1984). They too found that less procedures were done on clients admitted from nursing homes, predominantly an old-old population.

Early discharges may have been premature. The increase in readmission rates (from 0.6% in 1981 to 9.3 percent in 1984) would support this conclusion. Interestingly, the numbers of the young-old readmitted would suggest that this group suffered the most from early discharge even though their LOS declined the least.

Lastly, and perhaps a more critical issue given that the old-old population are headed by elderly women living alone, more of the old-old were discharged still requiring care for the episode of illness. More were referred to home health services (HHS) than any other age group (7.4% of the population, compared with 4.5% for the 70-84; 2.5% for those under 70). This establishes a situation in which attainment of necessary health care needs is at risk. This additional burden has been placed on a cohort that has the most difficulty of the three cohorts in even meeting activities of daily living (ADLs) (Rice and Feldman, 1983; Rosenwaike, 1985; and Suzman and White-Riley, 1985).

In addition to practice changes within the general hospital areas, changes in practices in special care units were noted since the implementation of DRGs. Both coronary and intensive care units (CCU and ICU, respectively) experienced sicker clients in 1984 than in 1981. The average number of diagnoses for Medicare patients in CCU increased 9.1 percent in 1984; in ICU, 60.9 percent. This would suggest a better selection process. This is especially noticeable in CCU where the LOS increased almost six-fold (a lower LOS would suggest more clients admitted for one day observation). CCU is an area in which reimbursement may not have been as profitable as it was under costbased systems. This could also explain why admissions to CCU decreased the most for the less profitable Medicare patients. The proportion of 70-84 year olds admitted to CCU declined from 10.3 percent ($p < 0.0001$); the proportion of the old-old decreased from 9.5 percent to 8.6 percent ($p < 0.025$). Interestingly, the proportion of young-old patients, a more profitable cohort, actually experienced an increase, though nonsignificant, in admissions. Since DRG payments for Medicare clients are substantially below the costs of treatment in medical intensive care units (Butler, Bone, and Field, 1985) which CCU predominantly cares for, DRGs may jeopardize access to special care units for those elderly for whom it is anticipated that resource expenditure could be excessive (i.e, more than allowed for the DRG). The old-old are particularly vulnerable especially if administration shifts its emphasis to managing by DRGs.

A very significant increase ($p < 0.0001$) in ICU admissions occurred in all age groups. Surgical DRGs, cared for predominantly in ICU, are more lucrative (Smits and Watson, 1984); hence, it is not surprising to see an expansion in this service market. The average amount of time within ICU remained about the same. This may indicate inappropriate admissions, but a positive profit margin would permit this practice. Or, perhaps, older sicker clients are poorer surgical risks. The LOS may reflect more postoperative deaths within the unit.

QUALITY ISSUES: A policy concern is the impact of DRGs on quality of care within the Medicare market since the implementation of DRGs. Lohr and associates (1985) at RAND suggest an evaluation of 19 DRGs common to the elderly and represent conditions in which both admission and use of ancillary services are discretionary. Given incentives within the DRG reimbursement system and this discretionary component of care, practice patterns for these DRGs should respond more to prospective payment system effects. Because of the limitations of the framework of this presentation only selected DRGs from the proposed list will be presented. Table 4 displays the selected DRGs. A mixture of DRGs with positive and negative profit margins were chosen. DRG 39 and 336 (lens procedure and transurethral prostatectomy, or TURP) were chosen from the list also because of the implications on patterns of admission and discharge. Emphasis on LOS may have had a negative impact for patients having a lens procedure or a TURP. Since most lens procedures are now done on an outpatient basis, LOS may have been seen as a discretionary component of care that could be decreased without consequences; however, complications are possible and may have resulted because there was no consideration as to the reason for admission for this procedure initially. Lohr and colleagues suggest that early discharge for DRG 336 may lead to inadequate assessment of the potential for urinary tract bleeding or other serious complications.

The profit potential for a lens procedure is 61.5 percent; for TURP a loss of 2.5 percent could be anticipated in the 1984 market. Correspondingly, the service market for lens procedures expanded some 12 percent for those 70 and older; declined slightly (4.5%) for those under 70. The TURP market experienced a decline in admissions of the old-old, by 25 percent. Admissions for those 70-84 remained the same; however, for the young-old the market increased 100 percent. With both DRGs readmissions contributed to the makeup of this new market. In 1981 the young old experienced no readmissions for lens procedures; however, by 1984, 20.4 percent were readmitted. For the 70-84 year old, in 1981 only 1 person out of 2156 admissions was designated a readmission; by 1984, the percentage had increased to 19.2. For the old-old, in 1981, no one was readmitted; by 1984, 19.7 percent were. A similar pattern of increased readmissions is noted for TURP. For the young-old, in 1981 no one was re-admitted; by 1984, 6.7 percent. For the 70-84 year cohort, 0.7 percent experienced readmission; by 1984, 14.7 percent. The old-old experienced 0.9 percent readmissions in 1981; by 1984, those re-admitted represented 16.8 percent of the all TURP admissions for this cohort. Re-admissions probably occurred because of the emphasis on LOS; yet, it was costly for this Medicare client at least physically, and to the hospital financially as the institution would not have been reimbursed for this patient (In 1984, for a client re-admitted with the same DRG within 7 days the hospital would not be reimbursed; now the time has been increased to 15 days).

DRGs 89, 96, 134, and 336 (simple pneumonia, bronchitis and asthma, hypertension and TURP respectively) represent diagnoses that may not be profitable. As is seen in Table 4, the incentive became one of decreasing procedures for clients within these DRGs. Procedures would tend to increase a client's LOS in the hospital, a disincentive in a prospectively paid system. Not only were services decreased, but also compression in service markets occurred for all age groups in DRG 134, hypertension; and as already noted above, for those over 85 in DRG 336.

DRG 122, 127 and 138 (circulatory disorders with an acute myocardial infarction, congestive heart failure, and cardiac arythmias, respectively) demonstrate more profitable DRGs and their impact on various age groups (See Table 4.) All of these DRGs saw expansion in service markets in that more clients were admitted in each of these categories (For DRG 122, the service market expanded more for the young-old than for the other age groups. DRGs 127 and 138 saw increases in procedures for the young-old and those 70-84, but experienced decreases in procedures for the old-old. The decrease in numbers of procedures performed, although not significant, is a concern especially in that this may indicate a potential problem in the provision of necessary services for the old-old.

Changing hospital products were also noted after DRG implementation. Hospital products are defined as Chesney and Long (1986) have proposed; i.e. by discharge location which describes the amount of care still required for that episode of illness. Table 5 presents the findings.

Fewer people in all three age groups were discharged home, a completed product, in 1984. This finding was similar to Chesney's and Long's. The largest percentage discharged to long-term care facilities, such as Home Health Services (HHS), Skilled Nursing Facilities (SNF), and Intermediate Care Facilities (ICF) were the old-old, meaning more incomplete products were found among this cohort. Yet, this came at a time when the state had frozen Medicaid long-term care beds. Further, since the implementation of DRGs the federal regulations for Medicaresponsored payment for services, though unchanged, are tightening in interpretation of the definition of homebound (Interview, East Midlands District Nursing Director, 1987). Moreover, as Leader (1986) points out, HCFA's regulations focus on acute care provisions within the home in order to receive Medicare reimbursement. Thus, the potential exists that a client discharged with a chronic disease, more than likely the old-old (Rice and Feldman, 1983), may not receive needed services required to treat the incomplete episode of illness. Denial of payment for services may induce too much a burden on the elderly. Other sources of payment may not be available. The state's HHS to the poor are facing retrenchment due to cutbacks in funding. Some health districts delay, or in some instances deny, visits to those clients who have no source of income to pay for their visits.

IMPACT ON DYING: The only age group that experienced an increase in deaths were the young-old; however, in this age group more were cared for on an outpatient basis meaning that only the more severely ill were admitted to the hospital. Given the decrease in the LOS for the 70-84 and the old-old, a declining number of deaths in the hospital may reflect the advent of hospice services in the state since 1981.

CONCLUSIONS

Since DRGs set a predetermined price for an illness episode regardless of resources consumed, a financiallywise hospital response would be to institute practices that would conserve resource usage to survive a more economically stringent environment, and that appears to be what happened. All three populations experienced retrenchment in hospital services; yet inpatient services were reduced the most for the old-old.

Service markets expanded for more profitable DRG; contracted for less profitable. LOS emphasis promoted premature discharges; increased re-admissions, the potential for denial of access for long-term care patients; and fewer Medicare clients were discharged home as completed products.

A continuation of these trends that have produced retrenchment in services may cause undue hardship on the elderly, but especially for the old-old. Policy that is economically stringent may produce undesired results with longreaching, untoward effects. Given these findings in South Carolina, along with evidence reported in national studies on the DRG experience, future health policy efforts need to be examined in light of potential organization response.

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TABLE 1 -- Source of Admission, Percent of Cohort, By Age Group, by Year

ADMISSION SOURCE	1981 Number	1981 %	1984 Number	1984 %
Physician				
< 70	28,940	(63.2)	26,376	(60.9)
70-84	33,628	(62.0)	38,641	(61.6)
>=85	5,510	(54.4)	6,755	(58.1)
LTCF (SNF & ICF)				
<70	172	(0.4)	114	(0.3)
70-84	700	(1.3)	538	(0.9)
>=85	428	(4.2)	382	(3.3)
Other Hospital				
< 70	346	(0.8)	465	(1.1)
70-84	445	(0.8)	560	(0.9)
>=85	84	(0.8)	119	(1.0)
Outpatient Clinic				
< 70	22	(0.05)	812	(1.9)
70-84	30	(0.06)	922	(1.5)
>=85	2	(0.02)	189	(1.6)
Emergency Room				
<70	13,841	(30.3)	8,661	(20.0)
70-84	18,139	(33.4)	13,437	(21.4)
>=85	3,906	(38.6)	2,907	(25.0)
Other*				
>70	312	(0.7)	5,619	(13.0)
70-84	310	(0.6)	7,481	(11.9)
>=85	58	(0.6)	1,085	(9.3)

NOTE: All overall categories were significant ($p < 0.0001$).
* Mostly readmissions, according to SC Office of Cooperative Health Statistics

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TABLE 2 -- Selected Demographics, Percent of Population by Demographic Type, Overall Age, by Year

Characteristic	1981	%	1984	%
AVERAGE AGE (standard deviation)	70.2 (14.2)	100	72.1 (11.7)	100
SEX				
MALE				
< 70	22,327	48.8	21,988	50.8
70 - 84	22,487	41.5	26,643	42.5
> = 85	2,970	29.3	3,570	30.7
FEMALE				
< 70	23,428	51.2	21,292	49.2
70 - 84	31,745	58.5	36,102	57.5
> = 85	7,160	70.7	8,059	69.3
RACE				
WHITE				
< 70	33,890	74.1	32,442	75.0
70 - 84	42,595	78.5	48,929	78.0
> = 85	7,651	75.5	8,946	76.9
NONWHITE				
< 70	11,865	25.9	10,838	25.0
70 - 84	11,637	21.5	13,816	22.0
> = 85	2,479	24.5	2,683	23.1

TABLE 3 -- Hospital Practice Changes, by Age Group, by Year

	< 70	74-85	> = 85
LENGTH OF STAY (DAYS)			
1981	8.8	10.4	11.8
1984	8.3*	9.0*	10.0**
AVERAGE DX #			
1981	2.7	2.9	3.1
1984	3.2**	3.3**	3.5**
AVERAGE PROC #			
1981	1.2	1.3	1.2
1984	1.3**	1.3	1.1**
AVERAGE LOS IN CCU			
1981	4.0	4.2	4.1
1984	23.6**	25.1**	24.6**
AVERAGE LOS IN ICU			
1981	4.6	4.1	3.5
1984	3.9	4.3	4.0

** $p < 0.0001$
* $p < 0.01$

TABLE 4 -- Selected Practice Changes for Medicare Patients for Selected DRGs, by Age Group, by Year

DRG	TITLE	LOS	# of Procedures	% Profit Margin Potential
39	Lens Procedure			
	<70	(-) ****	(+) ****	
	70-84	(-) ****	(+) ****	
	>=85	(-) ****	(+) ****	(+) 61.5
89	Sim Pneu >=70, CC			
	<70	(-) ****	(-) *	
	70-84	(-) ****	(-) ***	
	>=85	(-) *	(-) ****	(-) 17.1
96	Bronch/Asth >=70, CC			
	<70	(-) ****	(-) n.s.	
	70-84	(-) ****	(-) n.s.	
	>=85	(-) **	(-) *	(-) 10.7
122	Circ Dis w/AMI			
	<70	(-) ****	(+) *	
	70-84	(-) ****	(+) n.s.	
	>=85	(-) **	(+) n.s	(+) 4.7
127	CHF			
	<70	(-) n.s.	(+) n.s.	
	70-84	(-) ****	(+) n.s.	
	>=85	(-) **	(-) n.s.	(+) 7.0
134	Hypertension			
	<70	(-) ****	(-) n.s.	
	70-84	(-) n.s.	(-) n.s.	
	>=85	(-) **	(-) ***	(-) 15.2
138	Heart Arry, >=70, CC			
	<70	(-) ***	(+) n.s.	
	70-84	(-) ****	(+) n.s.	
	>=85	(-) n.s.	(-) n.s.	(+) 25.4
140	Angina			
	<70	(-) ****	(+) n.s.	
	70-84	(-) ****	(+) n.s.	
	>=85	(-) *	(+) n.s.	(+) 16.0
336	TURP, >=70, CC			
	<70	(-) ***	(+) *	
	70-84	(-) ****	(-) n.s.	
	>=85	(-) n.s.	(-) n.s.	(-) 2.5

**** p < 0.0001
*** p < 0.001
** p < 0.01
* p < 0.05
n.s. Non-significant

TABLE 5 -- Discharge Location, by Age Group, By Year

PLACE	AGE GROUP	1981 #	1981 %	1984 #	1984 %
HOME**	<70	40,836	(90.6)	37,598	(87.3)
	70-84	44,565	(83.5)	49,819	(79.9)
	>=85	6,825	(68.1)	7,361	(64.0)
HHS**	<70	458	(1.0)	1,086	(2.5)
	70-84	1,055	(2.0)	2,820	(4.5)
	>=85	313	(3.1)	851	(7.4)
SNF	<70	434	(1.0)	359	(0.8)
	70-84	1,907	(3.6)	1,928	(3.1)
	>=85	1,030	(10.3)	1,172	(10.2)
ICF*	<70	105	(0.2)	93	(0.2)
	70-84	439	(0.8)	527	(0.9)
	>=85	284	(2.8)	378	(3.3)
SHORT-TERM HOSPITAL	<70	980	(2.2)	901	(2.1)
	70-84	1,089	(2.0)	1,059	(1.7)
	>=85	174	(1.7)	137	(1.2)
OTHER FACILITY**	<70	280	(0.6)	1,171	(2.7)
	70-84	359	(0.7)	1,852	(3.0)
	>=85	85	(0.9)	298	(2.6)
DIED	<70	1,761	(3.9)	1,709	(4.0)
	70-84	3,892	(7.3)	4,265	(6.8)
	>=85	1,298	(13.0)	1,318	(11.4)

Overall Category Significant: ** p < 0.0001
* p < 0.01

ROBUST OLD: HEALTH STATUS AND HEALTH UTILIZATION

Tamara Harris, National Center for Health Statistics
Mary Grace Kovar, Jacob Feldman, Richard Suzman

Although there is a growing recognition that a substantial proportion of older persons remain able into advanced old age, there exist few studies which describe this able population and examine the correlates of physical ability. In this brief paper, data will be presented to support the hypothesis that a substantial proportion of older persons remain vigorous into advanced old age with few medical problems and low levels of health utilization. Furthermore, analyses of biomedical correlates of this vigorous group suggest that the potential exists for increasing this proportion of fit older persons.

Methods

The data for this paper were taken from the Supplement on Aging to the 1984 National Health Interview Survey, a probability sample of the noninstitutionalized population of the United States. All National Health Interview Survey household members age 65 years and older and a one-half sample of those age 55-64 years of age were asked to participate in the Supplement on Aging. Over 90 percent of persons selected participated and over 80 percent were at least partial self-respondents.

The study population for this data consisted of 1,937 white persons aged 80 or older, 1,322 women, 615 men.

The outcome of interest, robustness or being physically able, was defined as no reported difficulty walking one-quarter of a mile, no reported difficulty stooping, crouching or kneeling, no reported difficulty lifting 10 pounds or walking up 10 steps without resting.

As with all National Health Interview Survey samples, this sample was a complex multistage probability sample. All prevalence estimates presented in this paper were weighted to represent the U.S. population of similar age, race and sex. The correlates of physical ability were examined in multivariate logistic models that accounted for the sample design in the calculation of the standard error.

Results

Physical Ability

The order of difficulty for the 4 items included in the definition of physical ability was similar for men and women, although women reported more difficulty on every item (Table 1). Sixty-eight percent of persons aged 80 or older reported no difficulty lifting 10 pounds, 57 percent no difficulty walking up 10 steps, 50 percent no difficulty walking one-quarter of a mile and 47 percent no difficulty stooping, crouching or kneeling.

Of noninstitutionalized persons aged 80 or older, 33 percent had no difficulty on all 4 of the items. This figure included 43 percent of the men and 28 percent of the women.

To give some idea of what this proportion might be if adjusted for the institutionalized population, the proportion physically able, was recalculated increasing the denominator by the weighted population estimate of the institutionalized population of white men and women aged 80 or older, assuming that none of the institutionalized population would meet the criterion for being physically able. These adjusted proportions are shown on the last line of Table 1. Even accounting for the institutionalized population, over one-quarter of all persons aged 80 or older met the definition of being physically able. This included 38 percent of the men and 23 percent of the women.

Although the rest of this paper focuses on the physically able group, it is important to realize the comparison group was quite heterogeneous with only 6 percent of men and 11 percent of women reporting being completely unable to perform all four items.

Medical Utilization and Physical Ability

Those who met the criteria for being physically able reported considerably less disability and medical utilization (Table 2). Thirty-seven percent of the physically able reported less than a week of bed-disability days in the past year contrasted with 68 percent of the comparison group; 84 percent reported no hospitalizations in the past year compared with 70 percent of the comparison group and almost 60 percent reported at most one doctor visit in the past year compared with 36 percent of the comparison group. All of these differences were statistically significant adjusting for age and sex.

Multivariate Correlates of Physical Ability

Correlates of physical ability were examined in a multivariate model. Although causal relationships cannot be demonstrated in cross-sectional data, the variables selected for the models were at least potentially antecedent to the reported physical ability. For the most part the relative odds shown are counter-intuitive as they represent the risk of being able in the absence of the disease.

Men were at least twice as likely to meet the definition of physical ability than women.

Persons with phone contact with friends in the prior two weeks were almost twice as likely to be physically able, even adjusting for the factors in the model.

Persons in all body mass index quartiles were more likely to be physically able than those who were in the heaviest quartile with relative odds ranging from 1.6 to 1.9.

In addition, those with no reported difficulty chewing, no reported hypertension and no reported diabetes were more likely to be physically able. Relative odds for difficulty hearing did not differ from the null value for persons aged 80 or older.

Relative odds were substantial for three biomedical variables in particular. Those without reported arthritis were three times more likely to meet the definition for physical ability. For persons age 80 or older, those without cardiovascular disease were almost two and a half times more likely to report being physically able. (Cardiovascular disease included the reports of stroke, angina, heart attack, coronary artery disease, or myocardial infarction.) Furthermore, those without difficulty with vision were at least twice as likely to meet the definition of being physically able.

Conclusions

Results from this brief paper suggest three major conclusions regarding physical ability in white noninstitutionalized persons aged 80 or older. First, one-quarter or more of noninstitutionalized older persons reported no difficulty on 4 items of physical ability. Second, this group reported significantly lower levels of bed-disability and utilization of health services suggesting that this group enjoys relatively good health status.

Third, correlates of physical ability potentially amenable to intervention included arthritis, cardiovascular disease, vision problems and body weight. Interventions aimed at prevention of these conditions or interventions aimed at altering the course of these conditions once they occur may have a major impact in increasing the level of vitality in older populations.

Physical ability-age 80 or older

	Total	Men	Women
Lift 10 pounds	68	82	61
Walk up 10 steps	57	67	53
Walk 1/4 mile	50	58	46
Stoop, crouch or kneel	47	55	43
Physically able	33	43	28
Adjusted for 1985 National Nursing Home Survey	28	38	23

SOURCE: National Center for Health Statistics

Estimates of health utilization over prior year

	Percent	
	Physically able	Comparison
Bed-disability days		
0-6	87	68
7 or more	13	32
Short-stay hospitalizations		
0	84	70
1 or more	16	30
Doctor visits		
0-1	59	36
2 or more	41	64

SOURCE: National Center for Health Statistics

Correlates of physical ability-age 80 or older

Multivariate	Relative odds* (95% confidence interval)	
Male gender	2.9	(2.0,2.4)
Phone contact with friends within 2 weeks	1.8	(1.3,2.5)
Body mass index		
First quartile	1.6	(1.1,2.3)
Second quartile	1.9	(1.7,2.9)
Third quartile	1.6	(1.1,2.3)
No difficulty with:		
Chewing	2.0	(1.4,2.8)
Hypertension	1.4	(1.3,1.4)
Diabetes	1.7	(1.0,2.9)
Hearing	1.1	(0.9,1.3)
Arthritis	3.0	(2.4,3.8)
Cardiovascular Disease#	2.4	(1.8,3.2)
Vision	2.3	(1.7,3.2)

*Adjusted for age and education

#Cardiovascular disease includes angina, myocardial infarction, heart attack, stroke or coronary artery disease.

SOURCE: National Center for Health Statistics

HEALTH STATUS VARIABILITY AMONG THE OLDEST OLD

Patricia A. Guhleman, Wisconsin Center for Health Statistics

The variability of disease that accompanies advancing age recurs as a theme in the literature on the oldest old. Research documents health-related differences between elderly age groups,[1] as well as heterogeneity within age groups.[2] The greater variability in the manifestation of diseases among the oldest old, relative to younger persons, has been attributed, at least in part, to:

--The selection of a unique group which has escaped the force of mortality at younger ages;

--The constellation of diseases which the individual has acquired over time;

--An interaction between changes that accompany aging and the probability or severity of disease; and

--An interaction between changes that accompany aging and the disease course which effect individual response to disease, as well as the response by health care professionals to the oldest old.[3]

As the evidence accumulates for a profile of the elderly as a group with diverse health-related needs, it becomes increasingly important to find ways to capture that heterogeneity in the collection and presentation of health data. Questions that call for answers include: Is it sufficient to provide the oldest old their own age-sex columns in routine statistical reports? What reporting adjustments are required in order to appropriately portray health status among the oldest old?

As a result of the selection processes that bring people into the hospital, disease variability among the sub-population of hospitalized persons is not the same as among the population as a whole. However, acute hospital care represents a critical dimension of health care for the elderly. Rates of hospitalization among the oldest old are more than three times higher than those in the total population. For substantial numbers of older persons, the need for expensive long-term care depends upon the quality of their acute hospital care. Thus, the manifestation of diseases among the elderly, and particularly the oldest old who experience hospitalization, bears directly on health care policy.

The concept of disease variability among the oldest old has been developed largely from a clinical perspective, often within a context of distinguishing between effects from aging per se and those from other factors. It is not, however, entirely clear how disease variability among the oldest old manifests itself in the aggregate profile of patients who are hospitalized in an acute care setting.

This report discusses results from preliminary efforts to identify disease variability among the oldest old from hospital based morbidity data. Morbidity is reflected by discharge diagnoses, coded according to the ICD-9-CM. Data are from the 1986 Wisconsin Hospital Discharge Survey, which is a major source of information about utilization, patient characteristics, and morbidity in the state. The sample consists discharged during March and September of 1986 from general and medical and surgical hospitals in Wisconsin. Annual estimates are based on a weighting factor, which was derived uniquely for each hospital. Contents of the state discharge survey are patterned closely after the National Hospital Discharge Survey.

Discharge diagnoses are compared for persons in three age groups (65-74, 75-84, and 85+ years) who were hospitalized in Wisconsin during 1986. Each measure involved looking at discharge diagnoses in some way. First, dispersions of primary, or first-listed, discharge diagnoses are compared for the three age groups according to major diagnostic categories. Secondly, the age groups are compared in terms of their concentration within a few, primary leading diagnostic categories, based on a finer level of disease classification. Next, multiple diagnoses are used as a means to explore disease variability among the oldest old. The number of diagnoses for a given hospital stay is examined, and comparisons made between the number of times selected diagnoses are listed as primary versus any-listed, i.e., including primary and secondary listings. The report concludes with an exploratory examination of the patterning of primary and secondary conditions for selected diagnoses.

Despite a relatively larger proportion of elderly persons in Wisconsin, utilization of acute care hospitals by the elderly is somewhat below the national average. Among Wisconsin's elderly population, there were 310 hospital discharges per 1,000 population aged 65+ in 1986; the average length of stay was 8 days. Nationally, the elderly discharge rate was 368 per 1,000 population, and the average length of stay was 8.7 days. Virtually no difference existed between Wisconsin and the national as a whole in the average number of diagnoses per elderly hospital discharge (3.8 and 3.9, respectively), or in the mortality rate of patients in hospitals (6.5 percent and 6.4 percent, respectively).

Measures of Disease Variability

1. Distributions Across Major Diagnostic Categories

The importance of distinguishing between the age groups among the elderly is confirmed through examining the distribution of three age groups (65-74, 75-84, and 85+) across the major diagnostic categories identified by ICD-9-CM Chapters. The ICD-9-CM contains 18 major diagnostic groups (Chapters) that are applicable to analyses about the elderly.

A set of matrices was constructed to compare each group with one another according to the distributions across the diagnostic categories. Males and females were considered separately. Although the magnitude of difference varies with the particular disease category, Chi-Square values based on the overall distributions are significant for each possible age group comparison.

The distribution of any one age-sex group across the diagnostic categories becomes more meaningful in comparison with similar distributions for other age-sex groups. The Index of Dissimilarity is a summary measure of the difference between two distributions, and is based on the absolute differences between the percents in each diagnostic category. Using males aged 65-74 years as the reference group, values of the Index of Dissimilarity for males 75-84 years and 85+ were 6.5 and 11.2. The values suggest that a fairly straightforward progression of increasing difference in the distribution across major diagnostic categories accompanies advancing age among males. A similar pattern existed in comparisons among females with females aged 65-74 as the reference group.

2. Concentration Among Leading Diagnoses

The second approach to the problem of identifying and describing disease variability among the hospitalized elderly also considers distributions among primary discharge diagnoses. The question raised here, is: To what extent are principal diagnoses of the oldest old patients concentrated within a few diagnostic categories? Because the variability that exists within diagnostic categories becomes hidden as the level of aggregation increases, diagnoses were classified according to the three-digit ICD Codes. The three-digit codes include 72 categories and represent more detailed descriptions of the general categories previously shown. Using this classification scheme, separate frequency distributions were constructed for each age-sex group, based on the primary diagnosis. The figures shown in Table 1 suggest that the leading five or ten primary diagnoses account for a larger proportion of hospitalizations among the oldest old, relative to the less aged; the degree of concentration is greater for women than men. For example, 52 percent of hospitalized males aged 65-74 had one of the ten most frequently listed diagnoses in their group. Among women, the comparable proportion for ages 65-74 and 85+ were, respectively, 46 and 62 percent.

Examination of the particular diagnoses that constitute the leading ten diagnoses suggests that many of them are similar across the age groups, especially for comparisons within the same sex groups. For example, among males, only one diagnosis, injuries, is unique to those aged 85+.

3. Multiple Diagnoses

Health status among the oldest old is often characterized by the presence of multiple conditions. As a result, distorted images may be produced by profiles that rely on the primary diagnosis. Although the first-listed diagnosis is intended to reflect the primary condition, consistency problems exist in the ordering of first and secondary diagnoses. The consistency problem is probably greater among the oldest old, where multiple diagnoses are common, than among younger persons.

The Wisconsin hospital discharge survey includes a maximum of five discharge diagnoses per patient (in contrast to seven on the national survey). As illustrated in Table 2, more than half of both males and females aged 85+ received the maximum number of discharge diagnoses. In comparison, about 38 percent of the discharges aged 65-74 had five diagnoses. Although the age contrasts are not dramatic, there is a clear age-related pattern of a larger number of diagnoses per patient with advancing age.

In contrast to the first-listed diagnosis, the total number of times a given condition is reported provides a more comprehensive estimate of the magnitude of a condition in the hospital setting.

The Wisconsin discharge survey indicates that the aggregate number of first-listed discharge diagnoses represents about one-fourth of all diagnoses. This a relatively small subset compared to overall magnitude of conditions. Among the most aged, those 85+, first-listed diagnoses reflect a slightly lower proportion of total-listed diagnoses than among the younger group of hospitalized elderly. This overall difference is simply another way to view the higher number of diagnoses among persons aged 85+ relative to younger persons.

Table 3 demonstrates how reliance on the primary diagnosis will underestimate the number of patients who experience a condition. The table shows the percent of patients with a given condition who have the condition listed first on their discharge reports. Two key points emerge from an overview of the data. First, among the oldest old, as well as among other age groups, the probability that a condition will be first-listed depends upon the condition. Second, the age-specific pattern of first-to-any listed percentages also depends on the condition. For some conditions, the probability of the condition being first-listed is greater among the oldest old than for younger elderly persons. In contrast, some conditions are more likely to be present as underlying reasons for hospitalization among the oldest old. In addition, no age-related patterns seems to exist for other conditions. Diseases of the respiratory system, the endocrine system, and injuries provide examples of types of conditions that are more likely to be reported as primary versus secondary among the oldest old in comparison to younger elderly persons with similar conditions. In contrast, among patients with diseases of the circulatory system or the digestive system, the oldest old are more likely to have these conditions reported as secondary rather than primary, relative to younger persons.

The clustering of particular combinations of conditions often serves an important diagnostic function. It is the mix of particular diagnoses at the level of the individual which probably comes closest to the concept of disease heterogeneity among the oldest old.

In an exploratory examination of disease clustering among the hospitalized elderly, patients were first sorted according to their primary diagnosis using the ICD-9-CM Chapters. Distributions and frequencies were then examined, given the primary condition. The overview suggested that the oldest old are more likely than the younger elderly to have secondary conditions for several classes of diagnoses, but age-related patterns vary for the class of primary and secondary conditions.

Table 4 illustrates one way to portray disease clustering among the hospitalized elderly. In that example, the data represent a subset of patients with a primary diagnosis of the circulatory system. Each of these patients' records was reviewed to identify secondary conditions. The secondary conditions shown in Table 4 are classified according to the major diagnostic categories from the ICD-9-CM chapters.

Data in Table 4 illustrate some apparent age-related patterns in the presence of secondary disease, given a circulatory conditions. On the one hand, there is a clear age-related pattern for the presence of genitourinary conditions among patients with a primary circulatory condition: the proportion of the most elderly with secondary genitourinary diagnoses is more than twice the comparable proportion for persons aged 65 to 74 years; persons aged 75 to 84 years hold a intermediary position. There is a similar age-related pattern for a secondary diagnosis of "symptoms", given a primary circulatory condition; however, the contrasts are less sharp than for secondary diagnoses of the genitourinary system. On the other hand, among persons with a primary circulatory condition, the oldest old are not more likely than the younger elderly to experience a secondary respiratory condition.

Table 5 provides another way to look at pairing of diagnoses among hospitalized patients. In contrast to Table 4, which focused on the sub population of the elderly with a first-listed circulatory system diagnosis, Table 5 contains information about the sub population with any-listed circulatory system diagnoses. It shows the percent distribution of first-listed diagnoses among each elderly age-sex group with circulatory system diagnoses. The first row in Table 5 represent the proportion of discharges in terms of first-listed relative to any-listed circulatory system diagnoses. Among the group of patients with circulatory system diseases, the oldest old are more likely to have secondary circulatory diagnoses than younger elderly patients; however, age-related patterns of primary diagnoses depend upon the condition.

Discussion and Conclusions

The distribution of the oldest old over the range of possible discharge diagnoses represents one dimension of differentiation among the group. The major advantage of this approach is to provide summary information for aggregate profiles. The preliminary investigation indicated that the distributions across major diagnostic categories do differ significantly for the age-sex groups considered. However, according to three-digit ICD codes, a larger proportion of the oldest old are concentrated into a smaller number of disease categories, relative to younger persons. At first blush, the greater concentration of the oldest old, compared to the younger elderly, into five or ten diagnostic categories suggests less disease variability among the older group. There are, however, reasons why this suggestion may not be warranted. Both the number of categories and their level of detail influence the outcome measures. In addition, measures which rely on the primary diagnoses probably contain more bias when applied to the oldest old than to younger persons; this is because multiple diagnoses are more common at advanced ages. Clearly, there is need to go beyond primary diagnoses in constructing morbidity profiles of the oldest old.

The preliminary look at multiple diagnoses among the hospitalized elderly indicated that no single age-related pattern summarizes disease variability among the oldest old. However, the need for more refined measures limits conclusions at this stage. For example, differences in the characteristics of the sub populations need identification for comparisons between age groups. Issues about heterogeneity among the oldest old could be fleshed out with attention to variability within the major diagnostic categories among patients with similar conditions.

Despite measurement limitations, this initial examination of disease heterogeneity among the oldest old leads to the following general conclusions: The measures, applied to persons who were discharged from short-term hospitals indicate that differences in disease variability between and within age groups are not the same for all conditions. The measures reveal many examples of greater disease variability among the oldest old, compared to the younger elderly. Sometimes, the contrasts between age groups are strong; sometimes they are not. But the measures also suggest that, in many ways, the experience of disease heterogeneity among the oldest old in hospitals is not very different from that among the younger elderly.

Epidemiological and clinical studies provide reasons why the mix of particular conditions among the oldest old sometimes differs from the types of disease clusters among the less aged. There is, however, a need to relate the clinical picture, with its emphasis on particular conditions to the aggregate picture of morbidity among the oldest old. The development of health care policy which is sensitive to the unique disease constellations among the oldest old needs to be guided by an understanding of how specific disease patterns, which are experienced by selected group, translate into the aggregate demand for health care. From a perspective of cost containment, it is particularly important to identify those needs in relationship to demand for hospital-based care.

Table 1. Percent of Hospital Discharges Due To Leading First-Listed Diagnoses, Wisconsin 1986

Rank Ordered Discharge Diagnoses*	Males 65-74	Males 75-84	Males 85+	Females 65-74	Females 75-84	Females 85+
	Cumulative Percent of Discharges					
Leading 5	32	33	38	28	34	43
Leading 10	52	52	57	46	51	62

*Diagnoses are identified by 3-digit codes according to the ICD-9-CM.

Table 2. Hospital Discharges by Number of Diagnoses, Wisconsin 1986

Cumulative Percent of Discharges

Number of Diagnoses*	Males 65-74	Males 75-84	Males 85+	Females 65-74	Females 75-84	Females 85+
5	38.5	49.0	51.3	37.7	48.4	52.6
4	57.4	67.6	69.6	57.7	68.0	72.1
3	75.6	82.1	84.1	75.5	82.6	86.1
2	89.7	92.3	94.4	89.4	93.4	94.9
1	100.0	100.0	100.0	100.0	100.0	100.0

*Diagnoses are identified by 3-digit codes according to the ICD-9-CM.

Table 3. First-Listed as a Percent of Any-Listed Hospital Discharges for Selected Diagnosis, Wisconsin 1986

Diagnostic Category	Males 65-74	Males 75-84	Males 85+	Females 65-74	Females 75-84	Females 85+
Selected ICD-9-CM Chapters	Percent					
Circulatory Sys.	51.6	49.0	44.0	47.5	45.8	44.7
Respiratory Sys.	36.7	38.6	49.6	41.9	42.5	48.3
Digestive Sys.	58.3	57.3	54.0	56.7	53.3	55.7
Endocrine Sys.	10.5	12.3	17.9	13.5	15.1	16.5
Injury/Poisoning	50.1	48.2	58.6	58.9	63.5	71.1
Selected 3-Digit Categories						
Ischemic Heart Disease*	34.5	22.4	10.6	37.6	21.9	13.1
Other Heart**	30.8	30.2	31.2	32.7	33.2	29.5
Cerebrovascular Disease	58.2	54.5	50.8	61.9	56.6	60.0
Fractures	77.1	73.0	85.6	83.6	82.0	89.2
Symptoms	34.4	26.5	25.4	34.8	32.8	31.6

*Includes ICD codes 411-414, and excludes rheumatic heart disease, hypertensive disease, and acute myocardial infarction.
**Excludes ischemic heart disease and diseases of pulmonary circulation.

Table 4. Selected Secondar Diagnoses Among Hospital Discharges with a First-Listed Diagnosis of the Circulatory System, Wisconsin 1986

Secondary Diagnostic Category*	Males			Females		
	65-74	75-84	85+	65-74	75-84	85+
	Percent**					
Respiratory Sys.	19.7	22.0	20.6	11.5	13.9	13.5
Digestive Sys.	6.7	7.7	10.4	8.5	9.2	8.8
Genitourinary Sys.	7.5	14.3	16.3	8.2	13.0	16.8
Symptoms	13.5	19.2	20.4	14.4	17.5	19.7
Injury	7.5	6.2	5.9	6.6	5.0	5.5

*Diseases are identified by the ICD-9-CM Chapters.

**Patients may have a secondary diagnosis in more than one category, but they are not counted more than once within a single diagnositc category.

Table 5. Percent Distributions of Primary Discharge Diagnoses Among Patients wit Any-Listed Diagnosis of the Circulatory System, Wisconsin 1986

Primary Diagnostic Category*	Males			Females		
	65-74	75-84	85+	65-74	75-84	85+
	Percent Distributions					
Circulatory Sys.	51.6	49.0	44.0	47.5	45.8	44.7
Respiratory Sys.	7.7	10.0	13.0	6.4	7.0	8.9
Digestive Sys.	8.6	8.3	7.6	7.9	9.0	9.1
Genitourinary Sys.	4.5	5.4	6.7	2.6	2.5	2.4
Endocrine Sys.	2.0	2.1	3.7	3.6	3.8	3.8
Symptoms	5.8	5.7	4.3	6.4	6.0	5.1
Injury	3.9	3.9	6.1	5.9	7.5	11.9
Other	15.9	15.6	14.6	19.7	18.4	14.1
Total	100.0	100.0	100.0	100.0	100	100.0

*Diseases are identified by the ICD-9-CM Chapters.

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Morbidity and Mortality of Dementia in the Oldest Old: Analyses, Trends and Projections from a Longitudinal Study

Miriam K. Aronson, Ed.D. and Wee Lock Ooi, Dr. P.H.[++]

INTRODUCTION

In the last two decades the mortality rate of the very old has shown a dramatic decrease (1,2) due both to successes in treating acute infectious disease and to improved management of chronic disease. This increased longevity is in some ways a mixed blessing; for persons of advanced age are increasingly at risk for dementia, an age-dependent malignant condition (3) which diminishes the quality of life that has been extended.

Dementia is a major public health problem of the elderly today and presents economic and social threats into the twenty-first century. The population group aged 85 and above is growing most rapidly and utilizing disproportionate amounts of medical resources. For instance, in 1986 care costs for dementia alone ballooned to $40 billion. Given current demographic trends, these costs are projected to approach $750 billion by the year 2030 (4). Clearly, concerted research efforts are needed to elucidate the etiology and means for better control of dementing illnesses (5).

BACKGROUND

The Bronx Aging Study (Senile Dementias: Risks and Course) was designed to explore risk factors associated with the development of dementing illness in the old old. This study was initiated in 1980 and involved an inception cohort of 488 old old volunteers from the northern and eastern tiers of the borough of the Bronx, New York City who were community-residing at the time of study entry and had an average age of 78.8 years. Each subject began the study free of dementia; all cases of dementia in this report are, therefore, incident cases.

The study is unique in that it provides longitudinal, comprehensive, biomedical and psychosocial data. This report will explore morbidity and mortality issues related to dementia.

METHODS

Subjects are evaluated annually. Annual evaluations include epidemiological, mental status, medical, neurological, neuropsychological, and functional components. For those with cognitive change, a dementia workup is performed. This workup includes an expanded history from a significant other, electroencephalogram with evoked potentials, a CT scan, and calculation of a modified Ischemic Score (6).

Dementia is diagnosed, per DSM-III criteria (7), with Alzheimer's disease diagnoses being based on NINCDS-ADRDA criteria (8). Those subjects who have experienced a cognitive change but do not meet diagnostic criteria for dementia, are maintained in an intermediate category, "major cognitive change." All comparisons between dements and non-dements exclude this major cognitive group. Neuropathological confirmation of clinical diagnoses is sought whenever possible. The cut-off date utilized throughout this report was December 31, 1985.

Morbidity and mortality information is obtained throughout. The sources of this morbidity/ mortality data include: subjects, significant others, hospital records, and death certificate reports. A network that involves a study social worker, nurse, project physician and data clerk has been established to systematically collect and verify this data. Morbidity events of interest include strokes (cerebrovascular events), myocardial infarctions (MI) and dementias, whereas for those who die, all-cause mortality is examined.

Incidence rates of various morbid conditions and of death were calculated, and expressed in terms of person-time units, namely: number of cases per 100 person-years.

While morbidity rates were calculated for all age and sex groups combined, mortality rates were partitioned by age at entry to the program (<80 years and ≥ 80 years) and by sex. As a supplement to mortality rates, survival amongst male and female study subjects by age at entry were analyzed by the life-table method, to obtain estimates of the risk of death. Kaplan-Meier plots were then used to permit visualization and comparison of

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[++] Albert Einstein College of Medicine, 1300 Morris Park Avenue, Bronx, New York 10461.

survival rates between demented and non-demented individuals.

A Stepwise Proportional Hazards Linear Regression (Option was Backward Elimination) was used to develop the best multivariate, predictive model for the outcome death. The algorhythm began with the following subject characteristics: dementia status as of the end of 1985 and baseline information on age (truncated), history of stroke, history of cancer, HDL (1_2), HDL (1_3), systolic blood pressure, the interaction between age and history of cancer, and the interaction between age and systolic blood pressure.* Only those variables that met the 0.05 significance level for entry into the model were retained by this procedure. Analytical programs for these analyses were conducted using SAS and BMDP statistical software.

RESULTS

Morbidity and Mortality

Table 1 shows that dementia ranks as a leading morbid condition in this aged cohort, even when compared to major cardiovascular events such as strokes and myocardial infarctions.

Table 1

INCIDENCE OF MAJOR MORBID CONDITIONS

(1980 - 1985)

Morbidity Type	No. cases (rate/100 person-year)
Stroke	26 (1.4)
MI	53 (2.8)
Dementia	56 (3.5)
Alzheimer's	32 (2.0)

As shown in Table 2, the mortality rate of demented individuals was 7.9 as compared to 5.6 for non-demented persons. The most striking difference between demented and currently non-demented individuals was for females under age 80, where the mortality rate of those who are cognitively intact is less than half that of their demented counterparts (o.1<p>0.05). However, males did not show this same pattern.

Table 2

MORTALITY (RATE/100 PERSON YEARS)

BY DEMENTIA STATUS, AGE AND SEX

(1980 - 1985)

Dements*

	Age <80 (n=6)	Age ≥80 (n=11)	Total (n=17)
Female	8.6	8.4	8.4
Male	5.3	7.1	6.5
Total	8.0	7.9	7.9

Non-Dements**

	Age <80 (n=34)	Age ≥80 (n=31)	Total (n=65)
Female	4.0	8.0	5.6
Male	5.4	6.7	5.8
Total	4.5	7.6	5.6

*Includes SDAT, MID and Other

**excludes Major Cognitive Change

Although the statistical power of the test is presently inadequate to detect significant differences (at p<0.05) between rates, the direction of excess mortality in dements is clear. Therefore, the most meaningful results are based on the Life Table and Cox survival analyses which follow.

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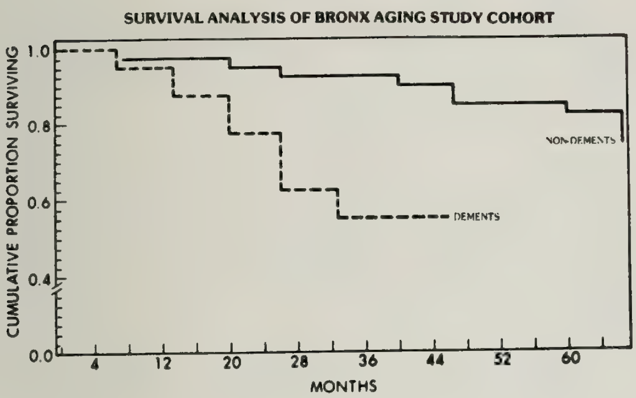
*Two dummy variables were created to analyze the utility of HDL as a predictor, comparing the highest tertile with the lowest HDL (1_3), and the intermediate tertile with the lowest HDL (1_2).

Life Table Analysis

The Actuarial Life Table technique for survival analysis was used to calculate survival probabilities and generate Kaplan-Meier plots of the cumulative proportion surviving within each group of demented and non-demented individuals (Figure 1).

FIGURE 1



The generalized Savage statistic or log-rank test for differences between survival curves demonstrates a significantly shortened life- expectancy among the group of demented subjects ($p<0.0001$).

Predictors

As shown in Table 3, dementia is one of the strongest and significant predictors of death ($p=0.011$), followed very closely by history of cancer ($p=0.004$), HDL (1_3) ($p=0.0033$), history of stroke ($p=0.014$), and age ($p=0.0002$). The interaction between age truncated and history of cancer was also found to be highly predictive ($p=0.0055$). Systolic blood pressure by itself, though significant ($p=0.0138$), contributed little towards explaining the variance in the outcome death. Other variables explored by this modeling procedure were total serum cholesterol, history of hypertension, history of smoking, functional status, and metabolic abnormalities, which were not found useful.

Table 3

COMPETING CAUSES OF DEATH

Stepwise Proportional Hazards

General Linear Model

Dependent Variable: Time to Death

Event Indicator: Death (n=61)

-2 Log Likelihood = 897.98

Variable	Beta	Std Error	P
Age	0.145	0.039	0.0002
Dementia	1.349	0.322	0.0011
HDL (1_3)	0.400	0.136	0.0033
Hx Cancer	25.349	8.799	0.0040
Age x HxCa	-0.311	0.112	0.0055
Sys BP	0.011	0.005	0.0138
Hx Stroke	0.906	0.368	0.0140

DISCUSSION

The Bronx Aging Study cohort of very old volunteer subjects have shown a survival pattern slightly better than that of the general population of comparable age in the United States (9), and most of the subjects report being satisfied with their lives. Although many subjects have become increasingly physically frail, the vast majority of our cohort remains free of dementia and has maintained a remarkably stable pattern of error scores on the mental status screening instrument (10). Thus, dementia is not an inevitable consequence of advanced age. However, one of our major findings has been a cumulative annual incidence rate of dementia of 3.5%, based on 56 incident cases.

The major cause of dementia in our study has been dementia of the Alzheimer type, accounting for 58% of cases. These incidence rates are comparable to those reported in other longitudinal studies of elderly subjects (11,12). We have also shown that dementia is not only a disabling condition, but is, in fact, life-shortening. Even when compared with other major competing causes of death among the elderly, such as cancer, stroke and serum HDL cholesterol, dementia still stands as a significant predictor of death. The time between earliest clinical diagnosis and death in our study has been over two years. This interim period is in fact a crucial time when care needs may escalate.

What is most striking about our results is that the incidence rate of dementia exceeds the rate of new myocardial infarction and that of stroke. Given this data, when the spectres of coronary heart disease and dementia are considered in perspective, dementia has the potential to replace cardiovascular disease as the most disabling and lethal problem affecting the elderly.

These findings have far-reaching implications for public health policy, planning and practice. The elderly are a growing segment of the population, with those over 85 experiencing unprecedented growth. The oldest old are most at risk for dementia and have the least physical and social resources and the lowest resistance to disease in general. Becoming demented presents an almost insurmountable set of problems for the individual, the family and society.

The unrelenting incidence of dementia will certainly result in a situation where there will be ever-increasing demands placed on the health and social service delivery systems by persons of impaired cognitive ability. Thus increased life expectancy may be transformed from blessing to burden by dementing illness.

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THE LONGITUDINAL STUDY ON AGING: SOME ESTIMATES OF CHANGE AMONG OLDER AMERICANS

Mary Grace Kovar, National Center for Health Statistics

The Longitudinal Study of Aging, the LSOA, is a collaborative project of the National Center for Health Statistics and the National Institute on Aging designed to measure change among older Americans. In particular, the 1986 LSOA Reinterview of people who were age 70 and over when first interviewed in 1984 was designed to measure change in functioning, such as change in ADLs and living arrangements, moving while remaining in the IADLs, and in the community or into and out of nursing homes, for example.

There were 5,151 participants age 70 and over in the 1984 Supplement on Aging to the National Health Interview Survey selected for reinterview in 1986. Today I want to give you the first national estimates based on that reinterview. They are simple, but they do suggest the change over two years.

Results

There were 17 million people age 70 and over living in communities in the United States in 1984 (Figure 1). Two years later, 82 percent were known to be alive; 11 percent were known to have died; 8 percent were not located. (It is likely that a disproportionate percentage of those not located had died and will be located through matches with the National Death Index.) People who were 80 and over in 1984 were more likely than those ages 70-79 to be either institutionalized or dead in 1986; they were equally likely to be living alone.

A number of research reports indicate that people living alone are at greater risk of being institutionalized than people living with others. While I also found that the reality is more complicated (Figure 2). People who had been living with a spouse only and people living with others for reasons not related to their health were indeed less likely to be in nursing homes or other institutions two years later than people living alone, but those who were living with others because of their health were more likely to be institutionalized. They were also more likely to have died. The inclusion of a measure of health modifies the basic conclusion.

The association between health status and place two years later is strong and is both statistically and programmatically significant (Figure 3). People who had no difficulty with either Activities of Daily Living (ADLs) or with Instrumental Activites of Daily Living (IADLs) in 1984 were more likely to be alive and living in the community two years later than people who had difficulty with IADLs only, who in turn were more likely than those who had difficulty with ADLs.

Among people age 70 and older, the receipt of help with an ADL or IADL was an even better predictor of place two years later than difficulty with either (Figure 4). If the person received help with an ADL, 27 percent were known to be dead two years later and 11 percent were in institutions. In contrast, among those with difficulty with either an ADL or an IADL but no help, 12 percent were dead and 4 percent in institutions; among those with no difficulty with either only 7 percent were dead and 1 percent in institutions two years later.

However, even among people receiving help, there were some whose health status improved, or at least did not worsen (Figure 5). Of those receiving help with an ADL in 1984, 7 percent had no difficulty with any ADL two years later. Of those receiving help with an IADL, 30 percent still had no difficulty with any ADL two years later.

Discussion

These are very simple presentations from an extensive dataset. They include no multivariate analyses. However, some work with adjusting for age reveals that health status is the overwhelmingly best predictor of where an older person will be two years later. Conclusions based on age-adjusted data of health status are identical with those that would be drawn from the data on health status without adjustment.

This suggests that research reports based on demographic data only without any control for health status could be misleading. We should not be surprised. Years ago Ron Anderson said that the important predictor in use of health care was illness. Demographic characteristics modified the rates of use of health care, but the influence of these "enabling" characteristics was minor compared to whether the person was sick. The same is true for older people; those who can continue living in the community do so; people who do not need long-term care, do not go into nursing homes. Those who are sick and need care over a long period may go into nursing homes. Whether or when they do will be modified by whether they have someone to care for them.

There is a suggestion in these data that there is a limit on how long people can care for a very sick person. Among those receiving help with an ADL in 1984 and known to be alive in 1986, 16 percent were in institutions. This suggestion needs to be investigated more fully from the LSOA and other data.

Even from this very simple presentation, it should be clear that some people who are relatively old, age 70 and older, have enormous resiliency. Some people were in better health (as measured by moving from receiving help with at least one ADL to having no difficulty with any ADL) two years later than they had been when we first talked with them, and many had not changed. The LSOA interviewers had their perceptions of aging changed by the experience of interviewing these people. They were nervous and scared when they started and enthusiastic and ready to do it again when they finished. I wish more people could have that experience.

This resiliency also needs more extensive investigation. For reasons that we too little understand, some people are able to overcome adversity. While they survive, they live as independent members of the community—age has little to do with it.

Instead of concentrating so much on negative aspects of the environment and on ill health, we should begin to investigate the epidemiology of surviving into an active productive old age. We have expended a great deal of effort on postponing death. We need to spend at least as much on the etiology and postponement of disability.

Figure 1

Status in 1986 for people who were age 70 and over in 1984 by age in 1984

Status in 1986	Total	Age in 1984	
		70-79 years	80 years and over
		Population in thousands	
Total	17,335	12,501	4,834
		Percent of population	
Alive	81.5	84.2	74.6
Alone	31.4	31.2	31.8
With others	47.0	51.1	36.2
Institution	3.2	1.8	6.7
Dead	10.9	8.3	17.6
Unknown	7.6	7.6	7.8

SOURCE: NCHS, Longitudinal Study of Aging, 1986

Figure 2

Status in 1986 for people who were age 70 and over in 1984 by living arrangements in 1984

Status in 1986	Total	Living arrangements in 1984				
				Other than spouse		
		Alone	Spouse only	Total	Health reasons	Other reasons
		Population in thousands				
Total	17,335	6,351	6,963	4,021	1,260	2,761
		Percent of population				
Alive	81.5	81.7	83.3	78.0	69.1	82.0
Alone	31.4	70.8	7.6	10.2	6.3	12.0
With others	47.0	5.8	74.0	63.6	53.3	68.3
Institution	3.2	4.2	1.7	4.1	9.5	1.7
Dead	10.9	9.3	10.3	14.5	24.0	10.2
Unknown	7.6	9.0	6.4	7.5	6.9	7.8

SOURCE: NCHS, Longitudinal Study of Aging, 1986

Figure 3

Status in 1986 for people who were age 70 and over in 1984 by status in 1986

Status in 1986	Total	Difficulty with		No difficulty
		ADL's	IADL's only	
		Population in thousands		
Total	17,335	4,550	1,856	10,928
		Percent of population		
Alive	81.5	72.3	80.0	85.6
Alone	31.4	27.5	33.2	32.7
With others	47.0	37.3	43.1	51.6
Institution	3.2	7.4	3.8	1.3
Dead	10.9	20.0	11.6	7.0
Unknown	7.6	7.7	8.5	7.4

SOURCE: NCHS, Longitudinal Study of Aging, 1986

Figure 4

Status in 1986 for people who were age 70 and over in 1984 by status in 1984

Status in 1986	Total	Status in 1984			
		Difficulty with ADL's or IADL's			No difficulty
		Help with		No help	
		ADL's	IADL's only		
		Population in thousands			
Total	17,335	2,016	2,771	1,619	10,928
		Percent of population			
Alive	81.5	66.1	79.3	76.8	85.6
Alone	31.4	15.5	33.2	39.3	32.7
With others	47.0	40.2	41.3	33.4	51.6
Institution	3.2	10.5	4.7	4.1	1.3
Dead	10.9	26.9	13.9	12.2	7.0
Unknown	7.6	6.9	6.8	11.0	7.4

SOURCE: NCHS, Longitudinal Study of Aging, 1986

Figure 5

Status in 1986 for people who were age 70 and over in 1984 by status in 1984

Status in 1986	Total	Status in 1984			
		Difficulty with ADL's or IADL's			No difficulty
		Help with		No help	
		ADL's	IADL's only		
		Population in thousands			
Total	17,335	2,016	2,771	1,619	10,928
		Percent of population			
Community	78.3	55.7	74.6	72.7	84.3
No ADL's	49.9	6.8	29.9	30.6	65.8
One plus ADL's	28.4	48.9	44.7	42.0	18.5
Institution	3.2	10.5	4.7	4.1	1.3
Dead	10.9	26.9	13.9	12.2	7.0
Unknown	7.6	6.9	6.8	11.0	7.4

SOURCE: NCHS, Longitudinal Study of Aging, 1986

HOW A WORLD OF FALLING DEATH RATES COMPLICATES THE PREDICTION OF DISABILITY PREVALENCE

Ernest M. Gruenberg

The Falling Death Rates

My paper differs in one respect from most at meetings sponsored by the National Center for Health Statistics. They have lots of slides with lots of data. This has few slides and a very little bit of data that raise a few questions about the future health of the oldest old.

Figure 1 is from Jacob Brody's Nature[1] paper. It reminds us that for eight decades U.S. death rates have been falling rapidly, and Figure 1b shows that the elderly have shared in this drop. In both graphs the top line shows the men, the lower line the women.

More Rapidly in Some Subpopulations

The distance between the lower women's line and the higher men's line gets greater in more recent years. The linear scale would produce this appearance even if the proportional drops in rates of the two sexes were equal. However, the fall in women's death rates has actually outstripped the fall in men's and the linear scale only exagerates this differential fall in mortality rates. Because of that increasing spread between the men's and women's death rates, women are coming to occupy an ever larger proportion of the elderly population.

Among People with Some Chronic Conditions

Suppose that the people with some chronic conditions had more rapidly falling death rates than other people. Then they too would become a larger proportion of the population; that is, these conditions would become more prevalent. Chronic conditions have a long duration because they don't kill quickly; people don't recover from them because you can't cure them. If a condition that was incurable becomes curable then it is no longer chronic.

If the death rate of a population with a chronic condition falls more rapidly than the death rate of the rest of the population, the condition's prevalence would tend to increase.[2]

Two Examples: SDAT and Down's Syndrome.

The data that raised this issue is from Professor Olle Hagnell's Lundby studies in southern Sweden[3]. It is a cohort of the total community of two parishes of about 2500 people interviewed in 1947 who are still being followed. The heart of the Lundby data base comes from mental disorder morbidity survey but incorporates all health data available such as known alcoholics from Temperance Board reports.

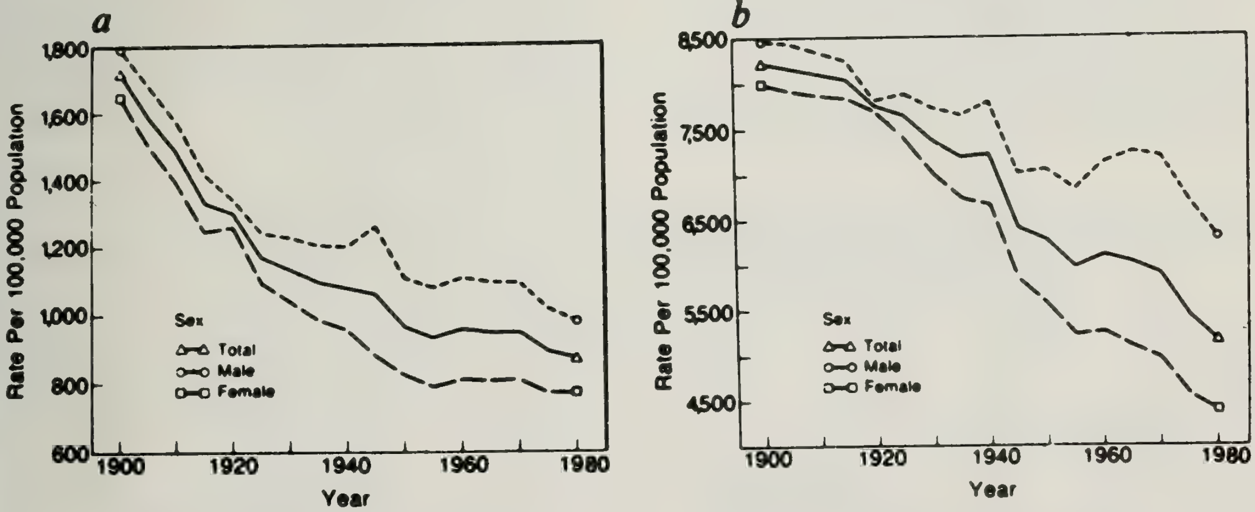


Fig. 1 *a*, Mortality rate for years 1900-79, by sex (all ages).

b, Mortality rates for years 1900-79, by sex (ages 65 and over). Source: National Center for Health Statistics, various volumes of *Vital Statistics of the United States.*

In Brody, JA: Prospects for an Ageing Population. Nature 315, p.463: June 6, 1985

Figure 2 shows data from two successive cross-sectional counts of the number of people with Senile Dementia of the Alzheimer type, referred to as SDAT. One was in 1947 and the other in 1957. The more steeply declining lower curve indicates that there was poorer survivorship among the SDAT cases found in the 1947 cross-section than among the SDAT cases found in the 1957 cross-section. The 1957 cases died less rapidly than did the 1947 cases. This means that the death rate in the SDAT subpopulation had fallen. Is this just another example of widespread falling death rates or did the death rates among the SDAT cases actually fall more rapidly during this time period? Perhaps the whole laboratory population's death rates were falling similarly.

Figure 3 shows that there is hardly any difference between the slopes of the two curves. The 1947 SDAT mortality and the 1957 SDAT mortality had decreased but the general population's overall mortality had hardly changed.

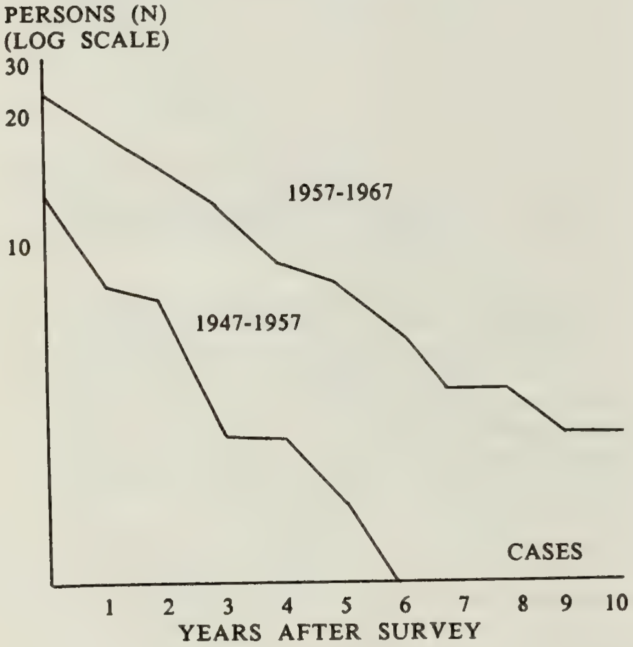
Figure 4 shows both pairs of curves at once so one can see that the later birth cohort's SDAT cases had an improved life expectation. Their nondemented age mates in the same population show no such improvement - the two survivorship lines are practically parallel.

The contrast between the upper pair of curves and the lower pair also illustrates the long known fact, now reconfirmed by Dr. Aronson with new data from the Bronx: demented people die sooner than do their age-mates.

This finding, that the presence of SDAT decreased life expectation less in 1957 than it had in 1947, was serendipitous. A puzzle had arisen in the course of analyzing the data that had been gathered during the 10 years to study the incidence of the different mental disorders in the laboratory population. In a methodological check the prevalence

Figure 2:

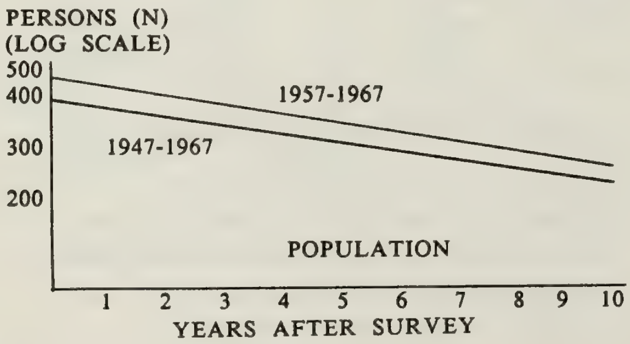
Survivorship in the SDAT Cases in the Years Following Two Morbidity Surveys a Decade Apart



Source: The Lundby Studies

Figure 3:

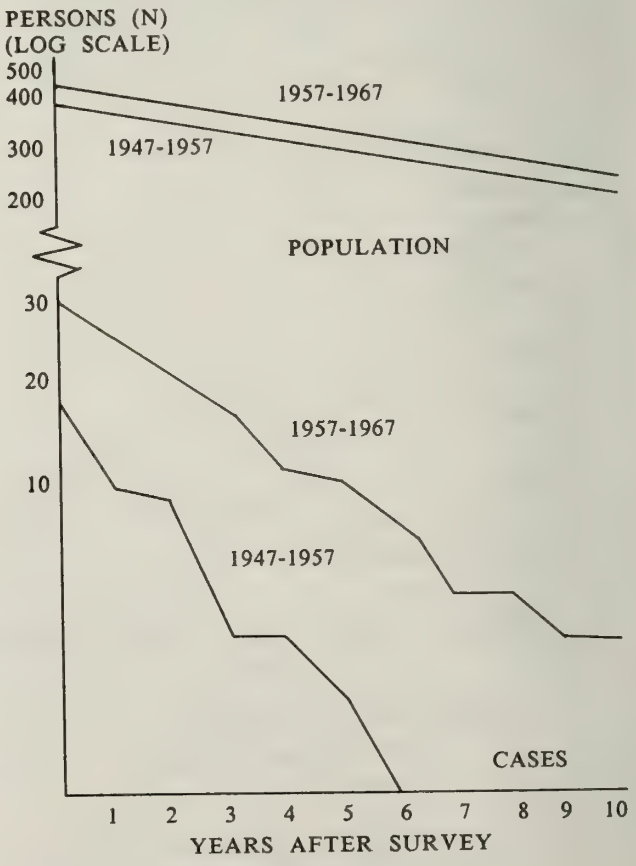
Survivorship in the Whole Study Population Over Age 60 During the Decades Following the 1947 and 1957 Prevalence Counts



Source: The Lundby Studies

Figure 4:

Survivorship of the General Population and of Senile Dementia Cases During Ten Years Following Prevalence Surveys



Source: The Lundby Studies

of all mental disorders at the two "cross-section dates" was compared with the surprising outcome that the crude prevalence proportion was larger in the later year. After convincing himself that the increase had not been due to a slippage in case ascertainment standards, he turned to others for suggestions as to possible substantive interpretations. The first simple step was to see if there were any concentration of new cases in an age group or sex. The second step was to see if the new cases were concentrated in a particular disorder.

Table 1 shows the result of that process: a doubling of SDAT prevalence in those over 60 during the decade.

Column (5) shows the number of SDAT cases to be expected if the 1947 prevalence had continued for each sex and each age group. In each age group in each sex a larger number occurs in 1957 than one would expect from the 1947 observations, even in the numerically very small groups over 80.

The bottom row shows that the prevalence had almost doubled from 3.2 to 5.7 %.

The mechanisms going on here illustrate a general principle relating chronic conditions and death.

"...persons rarely die of the disease with which they suffer. Secondary terminal infections carry off many patients with incurable disease." (Osler, 1935) That's what Professor William Osler said many years ago at the beginning of this century.

That view contrasts with Dr. Aronson's (the previous speaker) that dementia is a fatal condition. The diseases that produce chronic dementia are indeed associated with a shortened life expectancy. But that fact doesn't make it a cause of death. Dr. Aronson's assertions to the contrary notwithstanding, dementia's importance as a community public health problem is proportional to the extent to which people live prolonged diminished and burdensome lives rather than to the extent to which their death is hastened.

Osler's formula overemphasizes the importance of terminal infections, making it difficult to see its full implications.

The rising prevalence of Down's Syndrome shows nicely how terminal infections are not the whole story. (Down called this condition "mongolism", as many still do). It is now known to be a trisomy - a tripling of chromosome 21. It causes widespread defects of development throughout the organism, conspicuous mental retardation and serious structural defects in the heart. Upper respiratory infections are poorly resisted by these malformed organisms and are so frequently fatal the liveborn cases had a life expectation of less than four years. But in 1940 many of the bacterial causes of death were conquered, first by the sulfonamides and a little later by the antibiotics. Suddenly the life expectation of Down's syndrome newborns doubled within a decade and doubled again during the next decade. Just at the time that this wave of surviving Down's victims reached puberty in the 1960s, the cardiac surgeons began to conquer the cardiac anomalies associated with Down's syndrome that had been the main cause of death among the cases surviving to adolescence. So two technical advances (conquest of infections and conquest of heart anomalies) transformed Down's syndrome from a severe disabling condition of newborns and infants into a disabling condition of schoolchildren, adolescents and young adults. No one knows what proportion of this wave now in its 40s will survive to become burdens on geriatric services,

Hence we need to rewrite Osler's dictum:

> People rarely die of the conditions from which they suffer, but of the condition's fatal complications, some of which are fatal infections.

The corollary is:

> What thwarts a fatal complication of a chronic condition lengthens its average episode

Lowering a Condition's Incidence Rates Reduces Its Future Prevalence

Another reason the future health of the oldest old is hard to predict arises from another variety of technical innovation that prevents the chronic condition from beginning in the first place. Prevention of disease and disabling conditions is always public health's first priority. For example, we

Table I

The Increased Prevalence of SDAT in the Elderly Between July 1 1947 and July 1 1957 (Lundby, Sweeden)

	1947			1957			
Age	(1) Population	(2) Cases	(3) Prevalence rate (per cent)	(4) Population	(5) E*	(6) Cases	(7) Prevalence rate (per cent)
Men							
60–9	111	0	0	102	0	0	0
70–9	82	2	2·4	79	1·9	3	3·8
80+	20	3	15·0	45	6·8	8	17·7
Total	213	5	2·3	226	5·2	11	4·9
Women							
60–9	119	3	2·5	124	3·1	0	0
70–9	75	3	4·0	87	3·5	11	12·6
80+	35	3	8·6	33	2·8	5	15·1
Total	229	9	3·9	244	9·5	16	6·6
Men and Women							
Total	442	14	3·2	470	15·0	27	5·7

*Expected number of cases = Prevalence rate (3) × Population (4).

know that deaths from cerebral strokes are declining among the elderly but we do not know whether nonfatal strokes that produce multi-infarct dementias (MID) are also declining. If the **incidence** of these nonfatal strokes is declining we can expect future oldest olds to have a **lowered prevalence** of MID. But if fatal strokes are being transformed into nonfatal strokes (without protecting the brain from infarctions), then the oldest old will experience an **increased prevalence** of MID.

So predicting changes in the health of the oldest old requires an estimation of two types of technical innovation that will have opposite effects. One type extends the episodes of some chronic conditions by conquering some of their fatal complications. The other type reduces the frequency with which episodes of that chronic condition begin. Everyone knows that technical innovations are hard to predict. That is an important reason the future health of the oldest old is hard to predict.

So it is not practical to try to predict which type of change will occur before the other, it is easy to predict that there will be change. We have hard enough problems figuring out what changes have occurred in the last decade.

Setting Research Priorities.

Although the public health movement's technical competence does not include an ability to predict whether a prevalence-reducing innovation will precede a prevalence-raising innovation or vice versa; that does not mean it is a passive victim of past and future innovations. The public health movement has enormous experience in using what it does know to influence the probability that one type of innovation occurs next rather than the other. The future course of events will be influenced greatly by how we set research priorities.

We tend to recognize a rapid rise in the prevalence of a condition as producing a public health emergency calling for urgent action. When the rise is due to a sudden increase in the condition's incidence rate this generally occurs. We see this happening currently with AIDS despite the slow speed with which society responded to the terrible news the first few years. We then urgently seek ways to prevent the condition.

But when the prevalence doubles because a fatal complication is suddenly thwarted, we don't respond as quickly in recognizing that we should set an urgent priority to find a preventive. That is the current situation with respect to Alzheimer's disease and its associated dementia. It is the greatest threat to the oldest old's health and well-being, now and for the foreseeable future.

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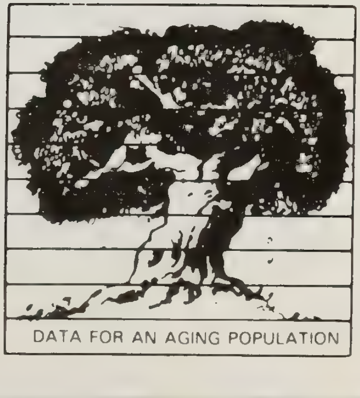
Session X

Estimating Needs for the Aging in Small Areas


DATA FOR AN AGING POPULATION

DIRECT METHOD AGE ADJUSTMENT AND AN AGING POPULATION

Douglas R. Murray, Wisconsin Center for Health Statistics

Direct method age adjustment, also known as age standardization, is a commonly used statistical technique that is most frequently used in the calculation of mortality rates. The technique has been subject to both praise and criticism ever since it was invented more than one hundred years ago. This discussion focuses on the practical aspects of the computation of Age Adjusted Mortality Rates (AAMR), and is based on empirical data analyses.

A useful definition of the age adjusted mortality rate was provided by Theodore Woolsey, then an assistant statistician in the Bureau of the Census in the early 1940s when he wrote a chapter on AAMRs in the classic Lindner and Grove publication on Vital Statistics.

"In its simplest form the direct method relates the age specific death rates of a given community to some population taken as a standard, to find for each age group what the expected number of deaths in the standard population would be if the age-specific mortality of the community applied. This is accomplished by multiplying the specific rate for each age group by the population for the corresponding group in the standard population. The adjusted death rate, direct method (MDM), is formed by adding the expected deaths for each age group and dividing the sum by the total population that was taken as a standard."

In discussing AAMRs, there are Professional, Programmatic, and Political issues to be addressed.

(1) Professional: What is the "ideal" way to do age adjustment? That is, if all necessary data were readily available to us, how would AAMRs be calculated?

(2) Programmatic: Since this is not an "ideal" world, what are the competing programmatic needs and practical considerations affecting the calculation of AAMRs? That is, what is the "optimal" approach to their calculation?

(3) Political: No organization plays a more salient role in the development and promulgation of Vital Statistics methodology than the National Center for Health Statistics. Therefore, it becomes all the more important to evaluate the current NCHS methodology.

The AAMR has at least three desirable features which make it a useful statistic for demographers, vital statisticians, epidemiologists, and health program administrators.

(1) The AAMR facilitates the comparison of populations with dissimilar age distributions that come from different points in time or, more frequently, from different geographic areas.

(2) The AAMR provides one easily manageable summary value, eliminating the need to deal with numerous age specific rates.

(3) With only one aggregate summary statistic, some of the problems associated with cell size in small area data analyses may be minimized.

There are two critical factors involved in the calculation of any AAMR. They are (1) the choice of a standard population, and (2) the selection of the age categories into which the data are arrayed. In the case of the National Center for Health Statistics, for example, a US 1940 standard population is used. The mortality and population data are then collapsed into 11 age categories, starting with less than 1 year, 1-4 years, and 10 year cohorts thereafter through 85+. The NCHS example serves to highlight the difficulties associated with these two factors.

The first consideration, the choice of standard population, has be thoroughly covered in the literature. Any discussion of age categories requires an understanding of the impact of standard population on the calculation of AAMRs.

In 1940, those persons aged 65 and older constituted only 6.8 percent of the population. In 1990, the Census Bureau estimates that people in the same age category will represent 12.7 percent of the population.

In 1940, there was relatively little difference between the sexes in the percent of the population age 65 and older: 6.7 percent of the males and 7.0 percent of the females. However, by 1990, it is estimated that 10.4 percent of the males and 14.9 percent of the females will be age 65 and older.

In order to assess the impact of standard population and selection of age categories on AAMRs, rates were calculated under a variety of circumstances. For the purposes of this analysis, data from approximately 40,000 Wisconsin deaths per year for 1979 through 1981 were averaged to obtain more stable values centered on 1980. This period was selected because counts of population were available by single year of age.

While comparably detailed mortality data for the nation as a whole would have been preferable, such information was not readily available. The data for the standard populations and for the denominators in the calculation of the age specific rates were obtained from Census publications. The analyses resulted in 252 separate calculated rates (6 standard populations times 14 cohort groupings times 3, for male, female, and total). All of the analyses were done on an IBM microcomputer using Lotus 123. The data are presented in Table 1.

The choice of standard population can have a profound effect on the calculated values of the AAMRs. For example, when an rate is calculated for all 1980 Wisconsin deaths using the NCHS technique of a US 1940 standard population and 11 age categories, a value of 518.7 per 100,000 population is obtained. Using a US 1990 standard population in an otherwise identical calculation, the rate is 898.5, more than 73 percent higher.

Using the 1940 standard population, the AAMR for Wisconsin men in 1980 is 80 percent higher than for women. When a US 1990 standard is used, the men have a rate that is only 69 percent higher than the women. It may be that there are situations where one could make women or men appear to have the higher rates, depending on the choice of the standard population. The reasons why this can happen are apparent given the radically changing age distribution of our society. Moreover, the "aging of America" has been primarily a female phenomenon.

In light of the changes in the national age distribution, it is recommended that the National Center and others adopt the US 1990 population as the new standard population. The 1990 standard would reflect the current age distributions as well as providing three or four years to make the transition.

There is a second methodological issue in the calculation of AAMRs which has received relatively little attention in the literature. This is the matter of the number and composition of the age categories to be used in calculating the age specific rates. Any number or combination of age categories can be used, ranging from one (a crude rate) to infinitely detailed.

While most are only of academic interest, the NCHS model with 11 cohorts -<1, 1-4, and 10 year cohorts thereafter through 85+ - is particularly important because of the number of analyses done by the National Center and many other parties using this model.

There are also three other cohort groupings that merit special attention.

1. The Bureau of the Census will evidently be publishing population estimates based on age categories consisting of: <5, 5-13, 14-17, 18-24, and 10 year categories thereafter to 85+. Given the potential availability of population data, this configuration must be carefully considered.

2. One important distribution, consisting of single years through age 89, 90-94, 95-99, 100+ should also be evaluated. These 93 categories are as close to being continuously distributed by year as was possible using published data.

3. An eclectic configuation consisting of seven age categories - <1, 1-14, 15-44, 45-64, 65-74, 75-84, 85+- also warrants close scrutiny.

In total, the impact of 14 different cohort groupings (not counting the crude rates) on AAMRs were examined for this study, ranging from as few as four to the high of 93. Each was examined in terms of six standard populations ranging from US 1940 to US 1990.

Some general conclusions can be drawn from these analyses. The more current the standard population, the larger the apparent rates for the same raw data. The age specific rates are always the same regardless of standard population. However, with age adjustment, the calculation of the number of expected deaths is based on the standard population. The larger the base of elderly, for example, the greater the weight associated with that age group. This results in a higher number of expected deaths and, hence, the higher the AAMRs with more current standard populations.

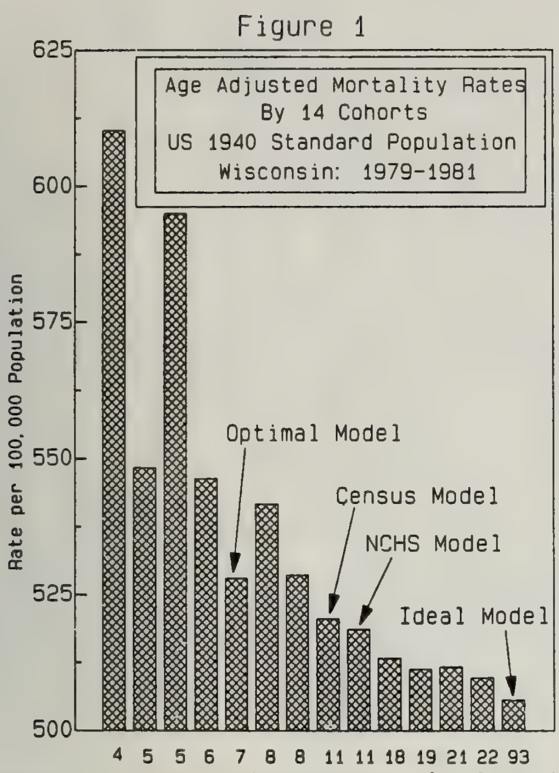
The standard population has a much greater effect on rates than the number of cohorts. This is by a comparison of AAMRs calculated using two standard populations (US 1940 and 1990) and 14 different cohort groupings. In spite of major differences in how the age categories are arrayed, those differences are small when compared with the impact of the standard populations. The changes in the overall population distributions are much more profound than how the age categories are aggregated within any given distribution.

While not as important as the choice of standard population, the selection of cohort groupings has a significant effect on the AAMRs. Using the US 1940 standard population, for example, the rates can vary from as high as 610 per 100,000 population when using only four cohorts to a low of 506 with 93 cohorts. (See Figure 1.)

More age categories provide a better fit to the data. The impact of skewness and other variations in population growth, such as baby booms, are minimized as more detail is added to the age category groupings.

As can be seen in Figures 1 (and 2), the general downward trend in the apparent rates toward the 93 cohort model is not a strictly linear one. With two models consisting of the same number of age categories, some age groupings will produce higher or lower rates than others. For example, two models were calculated using eight age categories and two using eleven.

Figure 1



Because of the differences in how the cohorts are grouped within each pair, the rates vary, sometimes quite substantially. In fact, the seven cohort configuration produces a rate below that of either of the eight cohort models.

The older the standard population, that is, the closer to 1940, the greater the impact of the cohort groupings on the rates. In the previous example using a 1940 standard population, the four cohort value was 21 percent higher than the 93 cohort figure. In otherwise identical analyses, this tapers off to nothing when the most current standard population is used. (Wisconsin has a slightly older population and slightly lower mortality than the nation as a whole - hence, the better fit to the US 1990 standard, even when using 1980 Wisconsin mortality data.)

A regression line plotted through the six values, demonstrates that the trend is not entirely linear. With the peak of the baby boom in 1960, this introduced a significant distortion in the overall population distribution. The four cohort model provides relatively little detail at older ages, resulting in higher ratios.

Given the impact of age groupings on AAMRs, the selection of appropriate age categories becomes very important. With only one age category, crude rates are subject to numerous distortions based on their population composition. To minimize the effect of various age categories, the "ideal" method is to use as much detail as possible, preferably one year age categories to 100 plus.

Most public health officials and program managers do not have ready access to detailed mortality and population distributions. When small geographic areas are involved, even sophisticated researchers find it difficult to obtain the population counts or estimates needed to calculate the age specific rates. This shortage of trustworthy population data for small geographic areas limits many epidemiological investigations or public health programs needing data at the most local level possible.

As a consequence of the small area data concerns, the "ideal" model consisting of 93 (or more) age categories is not practical in most situations. However, because of its detail and immunity to distortions in the population distribution, the 93 cohort "ideal Model" does constitute a standard against which other groupings of age categories can and should be compared.

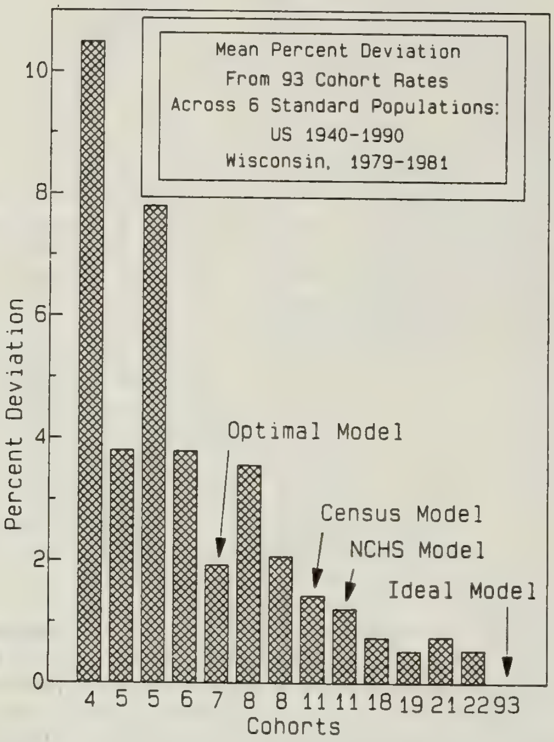
To evaluate the utility of the other 13 age groupings used in this study, two criteria were established. The first is the principle of parsimony. The fewer age categories, the better. The second is accuracy. The closer the rates generated by a given model to those of the "ideal Model," the better.

Accuracy was determined by calculating an AAMR for each of the 14 cohort groupings for each of the six standard populations, a total of 84 different rates. The percent deviation of each of these rates from the 93 cohort AAMR constituted the measure of accuracy. These deviations are measured only within a given standard population. For example, the seven cohort/1950 model was compared with the 93 cohort/1950 model.

In general, the more age categories there are in a given model, the closer their rates approximate the 93 cohort model. As can be seen in Figure 2, the four cohort model rates are 10.5 percent higher than the 93 cohort model. This tapers off to overestimates of less than one percent in those models with 18 or more age categories. Over the six standard populations, the Census and NCHS 11 cohort models provide estimates averaging 1.4 and 1.2 percent higher, respectively, than the "ideal" 93 cohort model.

While the models using more age cohorts tend to be more accurate than those using fewer, there are exceptions to the general rule. The seven cohort model works quite well, especially when seen in comparison with the eight cohort models. As with the eight cohort models, the seven cohort model has good detail in the older ages, as well as picking up infant mortality. Models with more detail in the high mortality

Figure 2



years tend to provide the best approximations to the 93 cohort model. This seven cohort model overestimates the AAMR by an average of 1.9 percent across six standard populations.

With Figure 3, the previous analysis was repeated, but limited to AAMRs calculated using US 1990 standard populations only. While average deviations across six standard populations can provide some indication of the robustness of the model, a more appropriate approach utilizes a current standard population.

Since the 1990 standard population more closely approximates the current age distribution in Wisconsin, the deviations are within a much narrower range. The largest deviation is 2.6 percent high. As is evident, several configurations closely approximate the US 1990 93 cohort model. These include both the Census and NCHS 11 cohort models, and the 18 and 19 cohort configurations. In this analysis, the Census model is a better approximation than the NCHS configuration.

However, the best approximation to the 93 cohort model is by the seven cohort model as it produces values only two one-hundredths of one percent high. The actual AAMRs with these two models were 899.8 and 899.7, respectively, per 100,000 population.

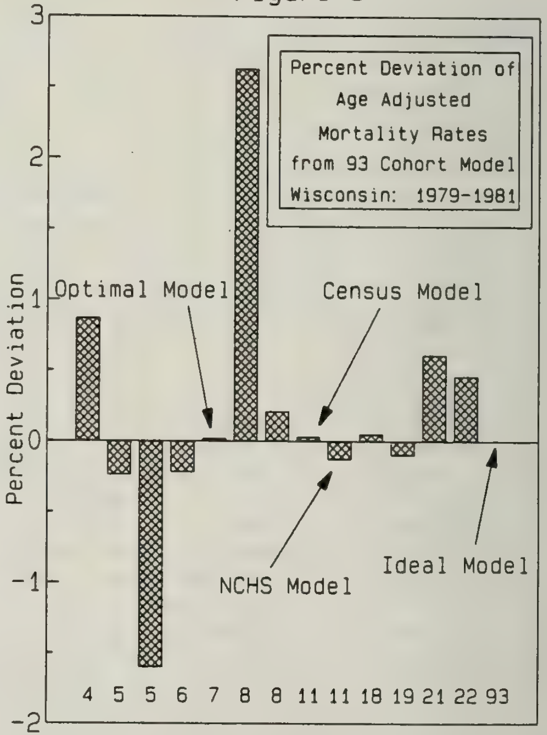
CONCLUSION

Clearly, the most important consideration in the calculation of AAMRs is the choice of standard population. To its favor, the NCHS model is as close to an empirical standard for the calculation of AAMRs as exists today. There is a large body of experience and literature behind it. Unfortunately, the US 1940 standard population is almost half a century old and bears little relationship to the population distribution of today. A change by the National Center to a new standard population is in order. Adoption of the US 1990 population distribution is in order.

The other factor in the calculation of AAMRs is the number and composition of the age categories. Not only is this important because of the statistical impact on the calculations but also because it is directly related to the availability of data, especially for small geographic areas.

When all the data needed are available, the "ideal" method of calculating AAMRs is to use single years of age mortality and population data. Greater detail minimizes the possibility that fluctuations in the data may affect the rates. The 93 cohort model (or some other highly detailed model) is the standard for evaluating other more parsimonious models.

Figure 3



While well established, the 11 age categories used by NCHS are not very useful for many of the other demographic and programmatic applications which population data must serve. Moreover, this configuration does not approximate the 93 cohort model as well as several other models.

If, for example, the Bureau of the Census will be using their 11 cohort model as the primary vehicle for presenting population estimates, especially for small geographic localities, researchers may wish to consider using these age categories for the calculation of AAMRs. The Census model did acceptably well in approximating the 93 cohort rates.

For many programmatic purposes, the Census model break at age 18, the age of majority, is useful. Unfortunately, it does not include the traditional category of 15 to 44 which is so important to demographic studies of fertility. Moreover, if this model is not a major policy initiative of the Bureau of the Census, population data will not be widely available in this configuration.

If that is the case, the "Optimal Model" has much to recommend it. With only seven cohorts, it is parsimonious. Fewer categories provide more stable age specific rates. Moreover, it approximates the 93 cohort - US 1990 model more closely than any other configuration. While lacking the break at age 18, it includes the 15 to 44 age category, making it most valuable for fertility research.

A common feature of all of the more successful models is the detail in the age distributions at ages 65 and older. This detail is what facilitates the accurate approximation of the 93 cohort model. Moreover, regardless of whether AAMRs are calculated or not, age specific population estimates and rates are essential for public policy, health, and research purposes.

At this point, it is appropriate to note that this analysis should not be considered the "answer" to the problems of calculating AAMRs. Rather, it is one possible methodology for getting at an answer. The many programmatic and statistical benefits accruing from the careful selection of a parsimonious configuration of age categories should not be underestimated.

A more thorough assessment of this methodology should use national mortality data with a variety of subpopulations, at the very minimum, sex and race. After all, a more detailed examination of the subject may yield other results. Be that as it may, statisticians should still aspire toward the goals of parsimony and accuracy to the fullest extent possible. Making AAMRs useful to both epidemiological researchers and program managers is the most important consideration.

TABLE 1

Standard Million	Male AAMRs	Female AAMRs	Total AAMRs	Deviation From 93 Cohort Model
4 Cohorts: 0-19, 20-34, 35-64, 65+				
US1940	767.1	478.9	610.3	20.67%
US1950	851.8	537.5	679.7	16.74%
US1960	901.0	574.0	721.1	14.72%
US1970	942.1	603.6	755.1	6.70%
US1980	1024.5	659.2	821.8	3.21%
US1990	1130.2	729.8	907.5	0.87%
			Mean:	10.49%
5 Cohorts: 0-14, 15-44, 45-64, 65-74, 75+				
US1940	715.2	411.5	548.4	5.98%
US1950	803.8	468.7	618.1	6.16%
US1960	863.7	509.2	666.1	5.97%
US1970	950.9	567.7	735.5	3.93%
US1980	1040.2	623.3	804.5	1.04%
US1990	1156.4	702.9	897.5	-0.24%
			Mean:	3.80%
5 Cohorts: <1, 1-14, 15-44, 45-64, 65+				
US1940	749.2	466.9	595.0	11.02%
US1950	837.5	529.3	668.2	14.76%
US1960	889.6	567.3	711.8	13.24%
US1970	940.7	600.8	752.6	6.34%
US1980	1024.0	657.5	820.3	3.03%
US1990	1102.7	713.3	885.3	-1.60%
			Mean:	7.80%
6 Cohorts: <1, 1-14, 15-44, 45-64, 65-74, 75+				
US1940	712.9	409.8	546.4	5.63%
US1950	806.3	470.7	620.4	6.55%
US1960	865.2	510.5	667.5	6.19%
US1970	947.9	565.4	732.9	3.55%
US1980	1040.0	623.2	804.3	1.02%
US1990	1156.5	703.0	897.6	-0.22%
			Mean:	3.79%
7 Cohorts: <1, 1-14, 15-44, 45-64, 65-74, 75-84, 85+				
US1940	699.6	388.0	528.1	3.67%
US1950	792.4	445.7	599.9	3.02%
US1960	852.5	484.4	646.6	2.87%
US1970	945.9	545.1	719.2	1.63%
US1980	1049.5	609.9	799.0	0.36%
US1990	1178.1	695.2	899.8	0.02%
			Mean:	1.93%
8 Cohorts: <1, 1-4, 5-17, 18-34, 35-64, 65-74, 75-84, 85+				
US1940	715.5	398.9	541.7	6.02%
US1950	810.3	458.2	615.3	5.68%
US1960	866.0	494.8	658.9	4.82%
US1970	944.4	546.4	719.6	1.67%
US1980	1049.9	611.7	800.5	0.54%
US1990	1206.8	713.1	923.3	2.63%
			Mean:	3.56%
8 Cohorts: <1, 1-4, 5-17, 18-44, 45-64, 65-74, 75-84, 85+				
US1940	700.5	388.3	528.7	3.80%
US1950	794.9	447.1	601.7	3.34%
US1960	854.2	485.2	647.9	3.07%
US1970	946.2	544.9	719.3	1.63%
US1980	1049.9	610.0	799.3	0.39%
US1990	1180.5	696.3	901.5	0.21%
			Mean:	2.07%

Standard Million	Male AAMRs	Female AAMRs	Total AAMRs	Deviation From 93 Cohort Model
11 Cohorts: <1, 1-4, 5-14,...85+				
US1940	689.4	383.8	520.6	2.15%
US1950	789.1	445.7	597.8	2.67%
US1960	847.4	483.4	643.2	2.33%
US1970	940.9	542.2	715.0	1.02%
US1980	1051.3	609.4	799.2	0.37%
US1990	1177.9	696.4	899.9	0.03%
			Mean:	1.43%
11 Cohorts: <5, 5-13, 14-17, 18-24,...85+				
US1940	687.1	382.0	518.7	1.82%
US1950	786.4	443.6	595.4	2.26%
US1960	846.2	482.2	642.0	2.14%
US1970	940.0	541.3	714.0	0.89%
US1980	1051.1	609.4	799.1	0.36%
US1990	1176.2	695.2	898.5	-0.13%
			Mean:	1.22%
18 Cohorts: 0-4, 5 Year Categories To 85+				
US1940	682.8	376.6	513.4	1.18%
US1950	782.9	438.0	590.4	1.40%
US1960	842.5	475.7	636.4	1.24%
US1970	941.5	537.4	711.8	0.57%
US1980	1053.1	604.9	796.6	0.05%
US1990	1184.1	693.9	900.1	0.05%
			Mean:	0.75%
19 Cohorts: <1, 1-4, 5 Year Categories To 85+				
US1940	680.6	374.9	511.4	0.85%
US1950	780.3	436.0	588.1	1.00%
US1960	840.8	474.4	634.8	0.99%
US1970	940.2	536.4	710.6	0.41%
US1980	1053.0	604.8	796.5	0.04%
US1990	1182.6	692.7	898.8	-0.10%
			Mean:	0.53%
21 Cohorts: 0-4, 5 Year Categories To 100+				
US1940	681.9	374.6	511.8	1.05%
US1950	782.1	435.6	588.6	1.09%
US1960	841.2	472.5	633.8	0.84%
US1970	942.0	539.4	713.6	0.82%
US1980	1055.5	604.5	797.2	0.13%
US1990	1191.0	697.9	905.2	0.61%
			Mean:	0.76%
22 Cohorts: <1, 1-4, 5 Year Categories To 100+				
US1940	679.7	372.9	509.8	0.72%
US1950	779.5	433.6	586.3	0.69%
US1960	839.4	471.1	632.3	0.59%
US1970	940.7	538.4	712.4	0.66%
US1980	1055.4	604.5	797.2	0.12%
US1990	1189.6	696.7	903.8	0.46%
			Mean:	0.54%
93 Cohorts: 0, 1...89, 90-94, 95-99, 100+				
US1940	674.8	369.5	505.7	0.00%
US1950	775.0	430.1	582.3	0.00%
US1960	835.8	467.6	628.6	0.00%
US1970	936.3	533.8	707.7	0.00%
US1980	1056.0	603.0	796.2	0.00%
US1990	1186.7	691.9	899.7	0.00%
			Mean:	0.00%

ESTIMATING AND PROJECTING NEED FOR LONG TERM CARE SERVICES IN MAINE'S 28 LONG TERM CARE ANALYSIS AREAS

M. Reid, Ph.D., P. Eckstein, S. Greenberg, M. Fleming, E. Naor, Maine Department of Human Services

Estimating the need for long term care services, both institutional and community-based, has become an increasingly important activity for State officials concerned with assuring quality care within tightening budget constraints. This is especially true for the State of Maine with its high poverty rate, its large proportion of "frail elderly," its sparse and rural population, and its already high Medicaid expenditures for long term care services. In many of these respects, Maine can be viewed as a forerunner of other states, or parts of other states. Thus, the planning work in long term care in Maine may be useful to many other states.

Selection of a Method

In 1986, the Maine Department of Human Services decided to develop a long term care plan which could serve as a guide for several of its units. The planning horizon was to be five years (1991). The Department received advice from the Maine State Health Coordinating Council during the development of the plan. At the center of the plan is a need estimation method based on the research of Professor William Weissert of the University of North Carolina's Program on Aging.[1] Professor Weissert's research was chosen as the basis for the method after reviewing methods reported in the literature or used by other states.

Several reasons led the Department to this choice. First, Professor Weissert provided a clear definition of the long term care population which was consistent with the ways that Department of Human Services programs define their clients. The definition focuses on a person's dependency on someone else for assistance in functioning. Second, this research was based on national surveys conducted by the federal government (National Nursing Home Survey and National Health Interview Surveys). These surveys identified the proportions of dependent people by several age and sex categories and the ways in which they were dependent. These proportions could then be applied to Maine-specific population data to estimate the number of dependent people in Maine in any year and the ways that they were dependent. Third, the methods produce estimates of the size of the dependent population for all age and sex groups, including the under age 18 groups. Fourth, Professor Weissert's work could be adapted to estimate proportions of the dependent population in Maine that would be served in institutions and in the community if Maine's dependent population were served in the way the national dependent population was served at the time of national survey. Fifth, the methods could be applied to available State and local data. No special surveys, program-based data or expert panels were necessary to use the methods. Finally, the methods provided point-in-time estimates of the dependent populations. This has advantages for program planning.

The definition of the long term care population which is used in the needs estimation method is:

> The long-term care population consists of all persons, regardless of age or diagnosis, who, because of a chronic condition, require or receive human help in personal care, mobility, household activities, or home-administered health care services. Personal care includes eating, continence, transferring (e.g., moving from bed to chair, or bed to floor), toileting, dressing, and bathing. Mobility includes walking and going outside. Household activities include meal preparation, money management, shopping and chores, excluding yard work. Home-administered health care services include injections, dressings, physical therapy, and other health care services.[2]

In this definition, the first two functional dependencies, those in personal care and mobility, are relevant need indicators for both institutional and community-based care. Some people are so dependent on personal care or mobility assistance that they can best be served in nursing or boarding homes. The second two dependencies, those in household activities and home-administered health care, are by definition relevant solely for community based settings. It should be noted that this definition is based on functional dependency alone. Thus, the need estimates which are produced do not include those without functional dependency who may need or be using nursing home, boarding home and community-based care. The most notable populations in this regard are the mentally ill and mentally retarded who are not functionally dependent. In developing actual and projected numbers of people served by long term care programs in Maine, care was taken to exclude nursing and boarding homes intended for the mentally ill and the mentally retarded.

The Method

As noted above, the long term care population is defined on the basis of "dependency on human assistance in daily functioning." Using that definition, Dr. Weissert prepared two analyses. First, he developed estimates of the proportion, or ratio, of dependent people by several age groups, race, and sex by combining data from the National Health Interview Surveys (NHIS) of 1977, 1979, and 1980, the National Nursing Home Survey (NNHS) of 1977, and the 1980 U.S. Census. The NHIS data provided information on the non-institutional population, while the NNHS provided data on nursing and boarding home residents. The U.S. Census data were used as denominators to calculate rates and percentages. Although there have been subsequent national surveys, information from them has not been analyzed for possible revision of the estimation techniques.

In addition to estimating functional needs, Dr. Weissert was able to select items from the 1977 NHIS and 1977 NNHS to estimate community, nursing and boarding home, and total service rates corresponding to personal care and mobility, the two dependency categories in the definition applicable to both institutionalized and non-institutionalized long term care populations. From these, he was able to estimate the proportions of the personal care and mobility dependent population that would be served in institutions and in the community.

In his second analysis, Dr. Weissert employed expanded dependency-related items from the 1979 and 1980 NHIS to generate community-based ratio estimates of dependency for household activities and home-administered health care services, as well as personal care and mobility by several age groups, race, and sex. This allowed estimation of a broader community population with functional needs. These four dependency types are defined as:

> . . . Personal care includes assistance in eating, continence, transferring, toileting, bathing, and dressing (those whose only problem was incontinence were excluded, again because they require no human assistance, e.g., stress incontinence in young women). Mobility includes assistance in walking and in going outside. Household activities include meal preparation, shopping, chores other than yard work, and financial management. Health services is a respondent-defined category. The most frequent response was injections, followed by changing of sterile dressings and a large number of very low prevalence items, including specific therapies.[3]

Three of these four categories conform to what is referred to in Maine as personal care assistance, homemaker services, and home health services. Assistance in mobility is not provided as a discrete service in Maine but is provided as one of the tasks in personal care assistance and home health services.

To develop a reasonably comprehensive estimate of the size of the dependent population, for 1991 the authors applied the dependency ratios for the appropriate age and sex groups to Maine's 1991 population projections for those same groupings. Because of Maine's very small minority population, only the ratios for the white groups were used. The national proportions of these personal care and mobility dependent populations which were in nursing homes were then applied to the 1991 estimated dependent population to produce estimates of need for nursing home care. This provided one half of the estimate of the 1991 dependent population.

The second half of the estimate was prepared by similarly applying the ratio estimates for the non-institutionalized dependent population from Dr. Weissert's second analysis to Maine's 1991 projected non-institutionalized population. These two halves were joined to produce the estimates of the dependent population in Maine for 1991.

The dependent population served in nursing homes would, by definition, be receiving formal services. A policy decision can be made regarding the relative proportions of this population which should be served in intermediate care and skilled nursing beds and in boarding care beds.

The estimates for the dependent population in the community make no distinction between those that receive care from organized agencies and professional care-givers and those that depend on natural systems, such as family, friends, or neighbors. To plan services, it is necessary to estimate the proportion of the non-institutionalized dependent population which should receive formal services. Based on research reported in the literature, the authors chose thirty percent to produce an estimate of the need for formal community services.

Local Area Analysis

The method described above produced statewide estimates of the dependent institutionalized and non-institutionalized populations for 1991. In themselves, these are valuable for planning services. However, estimates of need at the local level are of greater value. Accordingly, the analyses done at the statewide level were redone using local data to produce estimates of dependency for small areas. The small areas used in the analysis were Maine's 28 Long Term Care Analysis Areas (LTCAA). These areas were created several years ago to plan nursing home services and are now used to plan community-based services as well.

Table 1 shows the results of estimating the number of dependent people needing nursing home care in each LTCAA. Table 2 shows the estimates of the population needing community-based services in each area in 1991. It should be noted that the data for estimating the sex ratios in each LTCAA are not available and so the LTCAA estimates were produced using the white age grouping ratios alone. The statewide total (summing the LTCAA estimates) for the institutionalized dependent population was 2.2% less than the statewide estimate using the white age and sex ratios. The sum of the LTCAA non-institutionalized estimates was less than one-tenth of one percent greater than the statewide estimate using the white age and sex ratios.

The results of applying the method to the local areas suggested that most of the areas had more nursing home beds than the method would have predicted. Utilization data are not available for community-based services at the LTCAA level. However, the Department surveyed home care agencies in the fall of 1986 to collect utilization information at the county level. These data were compared to the results of applying the need estimates to county-level data. Each county was found to be underserved, with substantial variation among the counties in the degree of underservice.

Discussion

In summary, the method for estimating need for long term care services in Maine has a number of advantages - it is based on an operational definition using commonly accepted concepts, it relies on estimates of dependency developed from systematic national surveys, it estimates dependency for all ages (not just the elderly), it uses data which are usually readily available, and it combines estimates of need for both institutional and non-institutional services.

The method has some limitations. One is that it is based on national surveys conducted as long ago as 1977. When more recent NHIS and NNHS analyses are available, the method can be modified to use dependency ratios based on those analyses. Second, many factors have been found to be correlated with nursing home use, including poverty, living alone, migration, rurality, and climate. The authors are studying these with the intent of modifying the estimation method to account for these factors.

Applications

There are several practical applications of the needs estimation method described above. First, its definitions and the assumptions on which it is based are explicit and easily understood. It thus provides a systematic starting place for discussion by knowledgeable and interested parties. The method can be modified on the basis of those discussions to reflect local experience or conditions.

Second, it can be one basis for making certificate of need decisions In Maine, nursing home beds and home health agencies are regulated under the certificate of need (CON) program. The method provides an absolute measure of need and, by comparison with existing services, a means of measuring relative need so that competing CON applications can be evaluated.

Third, it can be used to determine where long term care services are most needed and thus be a guide to state funding and service development decisions.

Fourth, it can be an aid to manpower planning and support for training programs.

For the state, then, it provides a simple tool for joining comprehensive estimates of need for long term care services with service planning and development and the state budget process in this critical public policy area.

For private agencies seeking to establish or expand home care services, the method can aid in estimating staffing needs, in projecting annual caseloads, in identifying markets, and in budgeting.

Thus, there are many extensions of the method into public and private program and service planning and implementation.

Methodological Note

The authors also applied two other synthetic estimation techniques developed by Dr. Weissert and Alan Unger[4] to Maine data to estimate the number of mobility and personal care dependent people. These techniques used an age-based regression model and a mortality-based regression model. Dr. Weissert and his colleague developed these methods to allow greater precision in estimating dependency rates at the state level than may be achieved by applying the ratio estimates of dependency derived from the nationwide samples to state populations. They believed sampling errors contained in the ratio estimations might be magnified when the ratios were applied to subnational populations. They sought variables which had a strong local data base and which strongly correlated with personal care and mobility dependencies. Such variables could then "stand in" for personal care dependency and for mobility dependency for which there are no state level data. These variables could then be used in regression equations to predict dependencies. Rates for several variables were compared to the personal care and mobility dependency ratios derived from NHIS and NNHS surveys to see whether they were strongly correlated. Weissert and Unger tested sex and race as well as age as independent variables but found that they contributed little to the estimates of the dependent populations, relative to the effect of age. The second regression model used age-specific death rates as proxy measures for health status. The results of applying these two models to Maine data were very close to the results of applying the ratio estimation technique described in the paper. These findings support the use of this method.

Footnotes

1. "Estimating the Long-Term Care Population: Prevalence Rates and Selected Characteristics," Health Care Financing Review, Vol. 6, Summer, 1985, 83-91.

2. Ibid., p. 84.

3. Ibid., p. 87.

4. Data for Long-Term Care Planning: Application of a Synthetic Estimation Technique, The Urban Institute, May, 1983, (Unpublished Interim Report).

TABLE 1

State of Maine Projected Nursing Home Population By Long Term Care Analysis Areas on July 1, 1991

	Dependency[a]		Nursing Home[b]
NHAA	Personal Care	Mobility	Patients
1	909	575	380
2	789	506	330
3	504	319	219
4	1002	614	419
5	3344	2130	1397
6	1773	1124	740
7	465	292	194
8	319	202	133
9	1012	652	423
10	510	314	213
11	1271	806	531
12	623	396	260
13	537	338	224
14	1008	650	421
15	192	125	80
16	422	270	176
17	762	475	318
18	375	234	157
19	1629	1047	681
20	491	311	205
21	360	235	151
22	583	362	243
23	175	109	73
24	283	175	118
25	195	123	81
26	367	231	153
27	725	474	303
28	316	199	132
90	70	45	29
STATE	21011	13360	8775

Notes: [a] Dependency projections based on applying state by-age dependency proportions (as determined by Weissert ratio estimation method - see text) to 1991 population projections for age groups less than 65 yrs. old, 65-74 yrs., and 75 yrs. and over.

[b] Nursing home patients projected by summing expected nursing home patients among persons with personal care and mobility dependencies. Expected nursing home patients for each dependency category determined by multiplying estimated patient proportions times projected numbers of persons in each category. Estimated nursing home patient proportions used were 0.398 for personal care dependency and 0.031 for mobility dependency (from Weissert, Health Care Financing Review, 1985).

Source of population data: 1985-1994 Population Projections, Office of Data, Research, and Vital Statistics, Maine Department of Human Services. June, 1986.

TABLE 2

State of Maine Projected Total Community Based Population With Dependency Needs by Long Term Care Analysis Areas on July 1, 1991

NHAA	All Age Groups		Type of Dependency for Community Based Population				
	Total[a]	Community Based[b]	With Dependency[c]	Personal Care[d]	Physical Mobility[d]	Household Activity[d]	Home Health Services[d]
1	50050	48733	1459	541	208	523	187
2	49250	48012	1325	490	182	474	179
3	27950	27179	814	302	116	291	105
4	60300	58768	1666	615	232	597	222
5	195200	188474	5494	2033	775	1967	719
6	100700	97240	2817	1041	397	1009	370
7	24350	23934	728	271	104	261	92
8	16600	16355	508	187	74	183	64
9	64600	62766	1720	636	236	615	233
10	22900	22602	787	295	120	279	93
11	71850	69078	2015	745	285	721	264
12	36850	35590	1041	386	147	372	136
13	29150	28488	847	314	121	303	109
14	64200	61973	1679	618	229	602	230
15	12850	12605	329	121	44	118	46
16	25000	24645	722	268	101	258	95
17	37500	36231	1191	444	176	425	146
18	18750	18174	580	216	85	207	72
19	106450	100176	2732	1012	373	975	372
20	26900	26195	796	296	114	285	101
21	24150	22750	621	228	85	223	85
22	28550	27662	897	334	132	320	111
23	8250	8034	266	99	40	95	32
24	13100	12754	432	161	65	154	52
25	10100	9849	309	115	44	111	39
26	18900	18108	568	210	83	204	71
27	50300	48430	1246	458	165	447	176
28	16950	16272	494	183	71	177	63
90	4300	4180	119	44	17	42	16
STATE	1216000	1175257	34202	12663	4821	12238	4480

Notes: [a] Total population is equivalent to sum of projected populations in age groups less than 65 yrs., 65-74 yrs., and 75 yrs. and over.

[b] Community based population is the sum of community-based population by age group (Note a). Community-based population within each age group is calculated by multiplying projected area population in that age group times the statewide proportion of non-group-quarters persons in that age group, from the U.S. 1980 Census.

[c] Total persons with dependency is equivalent to sum of persons in each of the four dependency categories.

[d] Projections of persons within each dependency category calculated by multiplying projected population within age groups (Note a) times proportions of dependent within age groups by category (from Weissert, Health Care Financing Review, 1985).

Sources: Area population data from 1985-1994 Population Projections, Office of Data, Research, and Vital Statistics, Maine Department of Human Services. June, 1986. Proportions of statewide non-group-quarters population by age from: 1980 Census of Population, Vol. 1, Chapter D, Part 21: Maine. U.S. Census Bureau. Sept. 1983.

GEOGRAPHIC VARIATIONS IN HOSPITAL USE AMONG THE ELDERLY IN RHODE ISLAND

Jay S. Buechner, Rhode Island Department of Health
Alan B. Humphrey, University of Rhode Island

Introduction

Projecting the needs of the growing elderly population for hospital care requires a knowledge of the size and geographic distribution of this group, both current and projected, and of their geographic patterns of hospital use. In addressing the latter issue, the methods of small area analysis are traditionally employed.[1,2] These methods provide hospital utilization rates that are specific to defined hospital service areas and form the basis for further research into the origins of the variations in hospital utilization among geographic areas.

The investigation of geographic variations in hospital utilization rates is a multi-step process. First, the type of event to be examined is defined. Such events vary in specificity from a hospital discharge of any kind or a day of hospital care to a hospital discharge within a single diagnosis-related group (DRG) or with a particular surgical procedure. In order to examine the more specific types of events using existing hospital discharge data systems, much work has been done in examining the validity of the diagnosis and procedure coding in these systems.[2,3]

Next, the geographic areas for which utilization rates are to be produced must be defined. In dealing with existing hospital data systems, the choice of areas is limited by the geographic coding schemes employed in those systems. Usually, discharge data are coded to the county, zip code, or minor civil division of the patient's residence, as those items are easily obtained and are recognized by users of the data. They are also areas for which good population figures are generally available. In some studies, hospital service areas are then defined on the basis of these areas, typically employing a plurality rule operating on hospital market shares in each area.[2]

The third step in small-area analysis is the production of utilization rates for the selected geographic areas. These rates are typically adjusted to a standard population to account for differences in the age and sex distributions in the base populations being compared.[4] The rates so produced are then subjected to statistical tests in order to identify those differences that are unlikely to have occurred simply because of random variation. In some cases, these tests have incorporated a substantial level of statistical sophistication in allowing for multiple comparisons and underlying levels of random variation.[2,5]

In this work, the geographic patterns of hospital utilization by those age 65 or older are examined, using hospital discharge data for Rhode Island. The overall discharge rates and discharge rates for selected surgical procedures are computed. Age-adjustment has been employed to allow for differential utilization patterns within this age group. Rates for several measures of utilization are examined for the period 1979-1981, with selected comparisons to earlier and later years.

Of greatest significance, this work describes the first application of a set of hospital service areas developed for Rhode Island using advanced statistical techniques.[6,7] The determination of those service areas was by the application of cluster analysis to the hospital market shares in each basic geographic unit in the state so that geographic areas are grouped by their entire pattern of hospital utilization rather than by their dependency on a single hospital. This methodology has enabled the state's major metropolitan area to be differentiated into subareas that are meaningful with respect to hospital utilization and useful for examining differences in rates of hospital use among the populations of these subareas.

Methods

The methodology for producing the hospital service areas has been reported in detail elsewhere.[6,7] These areas were developed in order to provide improved differentiation of hospital service patterns in the Providence metropolitan area, which in earlier designations was considered a single area for purposes of secondary care planning,[8,9] and to provide all service areas with an improved scientific grounding. In addition, previous studies of variations in hospital use in Rhode Island[5,10] were based on city or town of residence (the minor civil divisions within the State), some of which have populations that are too small to support stable utilization rates.

In developing the hospital service areas used here, the basic geographic unit employed was the census tract, a unit developed for use with the United States Census which typically includes a small population with relatively homogeneous social and economic characteristics. Rhode Island is covered entirely by its 213 census tracts, and census tracts have been the basic geographic unit for coding patient residence on the hospital discharge database since 1971. The average population of a census tract in Rhode Island is under 5,000 people.

Census tracts were grouped into hospital service areas by applying cluster analysis to patient origin data for the years 1979-1981, a period chosen because of the availability of population data from the 1980 census. The patient origin data consisted of market share fractions for each hospital in each census tract. The cluster analysis formed groups of tracts which had similar market share patterns across all hospitals in the state, and statistical tests as well as inspection were employed to determine the optimum number of final clusters.

Patient origin patterns for the resulting hospital service areas were examined for all discharges and for the elderly. For the purpose of defining out-migration percentages, the principal hospitals serving each service area were defined so as to include hospitals geographically located within the service area plus the state's only tertiary-care general hospital if it had a market share of 20 percent or greater in that service area. Thus the broad service area of the tertiary-care institution was differentiated according to the patterns of use of other facilities. Out-migration rates so defined were then computed on the basis of discharges during the period 1979-1981. (Because of the study's focus on hospital use by the elderly, one institution in the state providing primarily obstetrical, gynecological, and perinatal care was excluded from the calculations of out-migration rates.)

Utilization rates for those age 65 and older were computed for each hospital service area for several selected measures of utilization. For the period 1979-81, the measures included all discharges, discharges with a principal procedure of prostatectomy (ICD-9-CM 60.2-60.6), and discharges with a principal diagnosis of lens extraction (ICD-9-CM 13.1). The procedures were chosen in part because of the relatively large numbers of such procedures performed and in part because comparable rates have been published for another state.[11] In order to examine the stability of the utilization rates over time, rates for all elderly discharges were also computed for the years 1974-76 and 1982-84. Population figures from the 1980 Census were employed in all rate calculations. Males only were included in the calculation of prostatectomy rates.

In computing utilization rates, adjustments were made for out-of-state care and for differing age distributions among the elderly in the various service areas. The adjustment for out-of-state care was based on discharges of Rhode Island residents from Massachusetts hospitals in 1980. (Rhode Island residents receive a negligible amount of care from hospitals in Connecticut, the only other bordering state.) The adjustment was accomplished by reducing census tract populations by a factor corresponding to the proportion of discharges from Massachusetts hospitals among those age 65 and over. Subsequently, utilization rates were age-adjusted to the state's population distribution using the direct method with five-year age groups in the range 65-84 years and an additional group for those 85 years of age or older.

Results

The optimum solution from the cluster analysis divided Rhode Island into ten hospital service areas on the basis of patterns of hospital market shares. These service areas have been described in detail elsewhere.[6,7] Characteristics of the service areas relevant to this work are presented in Table 1. The Providence metropolitan area has been divided into four service areas: Providence West, Providence North, East side, and East Bay. Two other service areas include nearby urban and suburban areas: Pawtucket and Kent. The other four service areas, Northern, Island, West, and South, include the more distant parts of the state. In each service area, the numbers of discharges among the elderly and the elderly populations are sufficient to support the analysis of utilization rates.

Out-migration rates are presented in Table 2 for each service area and for all discharges as well as for those of the elderly. In general, the rates of out-migration are highest in the urban service areas, where interhospital distances are small, and lowest in the service areas most distant from Providence. In particular, the Island service area, which includes Newport and other towns on Aquidneck Island,

Table 1:

Characteristics of Hospital Service Areas in Rhode Island

Service Area	Number of Hospitals*	1980 Census Population (Age 65+)	1979-81 Hospital Discharges (Age 65+)
Providence West	2	18,582	15,606
Providence North	3	20,280	17,520
East Side	1	3,671	3,606
East Bay	0	19,996	13,297
Pawtucket	2	16,115	13,629
Northern	2	10,987	11,217
Kent	2	20,412	16,575
Island	1	7,655	7,621
West	1	4,063	4,120
South	1	5,158	5,552
Total	15	126,919	108,743

*Including one facility providing primarily obstetrical/gynecological/ perinatal care and counting two geographically separated units of one hospital as distinct facilities.

Table 2:

Percentage of Resident Discharges from Other Than Principal Hospitals (Out-Migration Percentage) by Hospital Service Area, Rhode Island, 1979-1981

Service Area	Out-Migration Percentage All Discharges	 Discharges Age 65+
Providence West	42.7	46.3
Providence North	30.6	27.1
East Side	23.4	15.4
East Bay	52.0	49.5
Pawtucket	30.9	25.9
Northern	13.8	9.0
Kent	35.8	34.6
Island	6.7	4.5
West	20.6	14.8
South	32.4	29.1

represents a particularly self-contained hospital care system. The patterns of out-migration for the elderly mirror those of the population as a whole, except that smaller percentages of them seek care outside their service area, in general. The similarity of the elderly patterns to those for all discharges supports the use of these service areas for the elderly subpopulation.

Table 3 presents selected hospital utilization rates, adjusted for differential age distributions and for use of out-of-state facilities, expressed in relation to the crude rate for the entire State. Rates for total discharges (excluding hospital newborns) are presented for three time periods. There is substantial variation in these rates among hospital service areas; in 1979-81, the highest utilization rate observed was 72 percent higher than the lowest. In 1974-76 the difference was 82 percent; in 1982-84, it fell to 45 percent. This variation is superimposed on a rapidly increasing discharge rate, as the crude state rate for the elderly increased by 36 percent over the period. It should be noted that these rates are not adjusted for changes in population size or age distribution, for changes in out-of-state utilization, nor for changes in quality of residence coding in the hospital discharge data; however, estimates of these effects are small compared to the observed increase.

The patterns of variation are consistent over the time period examined. In each three-year period the minimum and maximum rates were found in the same service areas. Utilization rates in and near the Providence

Table 3:

Relative* Age-Adjusted Hospital Utilization Rates
for Discharges Age 65+, by Hospital Service Area,
Rhode Island, 1974-76, 1979-81, and 1982-84

	Relative Utilization Rate				
Service Area	Total Discharges			Lens Extraction	Prostatectomy
	1974-76	1979-81	1982-84	1979-81	1979-81
Providence West	1.06	0.96	0.94	0.95	0.89
Providence North	0.94	0.99	0.96	0.88	1.02
East Side	1.15	1.05	0.97	1.28	1.12
East Bay	0.77	0.80	0.87	0.83	0.74
Pawtucket	1.00	0.97	0.95	1.32	1.11
Northern	1.11	1.15	1.09	1.20	0.90
Kent	0.94	0.93	1.03	0.72	1.03
Island	1.41	1.38	1.26	1.15	1.52
West	1.11	1.23	1.20	0.99	0.83
South	1.11	1.24	1.22	1.58	1.36
State Crude Rate per 1000 Population	243.9	297.1	330.5	10.06	15.70

*Relative to State crude rates

metropolitan area were generally lower than in the outlying service areas in all time periods. Substantial changes in relative rates appear to be occurring in only a few service areas, notably in the East Side and Island areas. Again, these rates have not been adjusted for any population changes or changes in out-of-state utilization. Nevertheless, the evidence presented supports the existence of a stable pattern of variations in utilization rates over an extended time period.

The geographic variations observed in the utilization rates for discharges with lens extraction and discharges with prostatectomy are somewhat larger than the variations in the total discharge rate. In each case the highest rate observed was slightly greater than double the lowest rate observed. The patterns of variation in these rates were different than those observed for total discharges. Rates in and near the metropolitan area were not found to be generally below those for outlying areas.

Utilization rates for the same measures examined here have been published for New York State for the year 1981, using the state's 62 counties as the basis for small-area analysis.[11] (Most of the counties have elderly populations similar in size to the ten hospital service areas defined for Rhode Island.) Greater overall variations in utilization rates were found in the New York study than in Rhode Island rates for 1979-81. For total elderly discharges, the ratio of the maximum rate to the minimum rate was 2.38 in New York compared to 1.72 in Rhode Island. For prostatectomies the ratios were 2.48 in New York and 2.06 in Rhode Island, and for lens extractions the ratios were 5.40 in New York and 2.21 in Rhode Island. Given that 62 areas were employed in the New York study and only one year of discharge data was examined, the range from the minimum rate to the maximum rate would be expected to be larger in that study. Nevertheless, the disparity in the ranges for lens extraction rates stands out. A possible explanation can be proposed based on the coefficients of variation published for each rate investigated in the New York study: they are similar for prostatectomy rates and lens extraction rates despite the large differences in the ranges for the two procedure rates. Moreover, the coefficients of variation for these rates are similar in New York and Rhode Island. Since the coefficient of variation is a measure of the spread of all observations of a variable, the suggestion is that the maximum and minimum rates for lens extractions observed in New York are outliers not representative of the rates for the majority of counties and the overall pattern of variation is similar in the two states.

Discussion

This analytic effort has yielded two key elements for projecting the health care needs and examining the health care utilization patterns of the growing numbers of elderly in Rhode Island. One of these elements is a set of hospital service areas created on the basis of discharge data used in conjunction with sound statistical methods. These service areas have been shown to be appropriate for examining the geographic patterns of hospital use by the elderly subpopulation. In addition, the methodology for producing the service areas has provided a means for differentiating hospital utilization patterns within a metropolitan area formerly considered as one service area for secondary care despite containing seven hospitals.

The second element resulting from this work is a series of utilization rates for the elderly that are based on these geographic areas and therefore are useful for projecting utilization patterns and hospital care needs for the elderly on a small-area basis. The geographic pattern of the utilization rates for the elderly has been shown to be stable over an extended time period, and the ability to examine rates for discharges with specific surgical procedures has been developed. These elements provide the foundation for the use of such data in the areas of health care planning, research, and cost containment.

Acknowledgements

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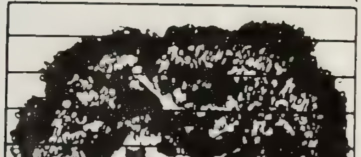
Session Y

Data Quality Issues



DATA FOR AN AGING POPULATION

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THE RELATIONSHIP OF COGNITIVE FUNCTION, HEALTH STATUS AND MOOD TO MISSING DATA AND INCONSISTENT RESPONSES IN AN INTERVIEW OF THE ELDERLY

Robert B. Wallace, Preventive Medicine and Environmental Health, University of Iowa

With greater recognition and interest in the health problems of the elderly as a public health issue, older persons are increasingly becoming the target of population-based surveys in order to assess the amount, trends and impact of these problems. At the very least, there is every reason to expect that all the data quality issues present in surveys of other age groups are also present here, but there are likely to be additional issues in this age group. Some important issues include access to the household, acquiring informed consent, the age difference between interviewer and respondent and perhaps the higher potential for non-participation due to a higher prevalence of illness or institutionalization.

Another major issue is the potential problem of cognitive decline and its effect on the quality of survey responses. The cognitive aspects of data accuracy are certainly important at all ages, but in the elderly there are special challenges and opportunities: cognitive status of individuals may be changing at a faster rate; there is a higher prevalence of central nervous system diseases and the use of drugs which alter neuro-psychological function; and it is sometimes a concommitant goal of surveys to assess cognitive function. In this report we will apply, from a population survey of the elderly, items relating to cognitive performance to evaluate the quality of data in that way.

The data presented here are from the Iowa portion of a group of collaborating surveys sponsored by the National Institute on Aging, entitled "Established Populations for Epidemiologic Study of the Elderly." (1) This is a cohort study intended in part to identify risk factors for morbid events, functional decline, institutionalization and death in persons 65 years and older. Our own target population was all persons in this age group living in two rural Iowa counties. Most of the data will be from the baseline household interviews conducted in 1982, with an overall participation rate of 80%. Data from the 15% of subjects with abbreviated or proxy responses will not be considered. Some information from a second household survey in 1985, with a 97% participation rate of survivors will also be offered. In an earlier analysis we showed that baseline non-participants had a higher 2-year mortality rate than participants (2), suggesting poorer health status in the former group. Respondents with proxy interviews, not considered here, also had a higher mortality rate than the others.

Two measures of data quality will be considered here: missing data and inconsistent responses. Missing data took the form of either "don't knows" or refusal to answer, according to survey design. This distinction was interpreted by the interviewer based on subject response. Interviewers were instructed to offer specific prompts when this occurred, but not to force responses when none could be offered. Table 1 shows examples of the refusal rates for selected items on the baseline survey. In general, these rates were gratifyingly low. By far, the highest refusal rate was the free recall memory test. There was a clear resistance to this activity, despite a long, careful explanatory lead-in. A smaller proportion refused to divulge their incomes, but this is a well-known problem. Per-item refusal rates for all other general categories were small.

Table 1
Refusal rates for selected items, baseline Iowa Survey.

Item category	Refusal rate
Free recall memory test	6.0%
Income	1.9
Functional status	<0.1
Depressive symptoms	
Social networks	
Hx of problem drinking	
Health history	
Medical services use	

A sampling of the "don't know" rates are shown in table 2. In general, these rates are also quite low, and the interpretation can be complex. For example, most of our subjects were native-born of mixed European ancestry, and ethnic identity is sometimes lost. Not knowing whether you can stand on one foot brings up the dilemma of assessing functional status by report, in that some potential maneuvers are never tested by the subject. Not knowing one's potential social network may similarly be

Table 2
"Don't know" rates for selected items, baseline Iowa survey

Item category	"Don't know" rate(%)
Standing on one foot without help	7.6
Ethnic origin	5.9
Availability of relatives in a crisis	3.9
Trouble remembering phone numbers	3.7
Ever taken digitalis preparation	1.8
Health history	<1.0
Other functional status items	
Presence of symptoms	
Medical services use	
Mood items	

due to its untested nature and not to cognitively inability to answer the item. Not remembering drug use or the perception of having difficulty remembering phone numbers may, however, at times reflect this inability, which we will pursue later.

Table 3 shows the "don't know" rates for participants of both the baseline and second personal interview three years later, examining selected items queried on both surveys. With only rare exceptions there were fewer "don't know" responses on the second interview, even though the respondents were now three years older. This suggests both a learning effect and a general accommodation to study purposes and activities.

Table 3
"Don't know" rates for selected items on baseline and third year personal interviews

Item category	"Don't know" rate (%) Baseline	 Third-year
Standing on one foot without help	7.6	3.3
Difficulty seeing a familial face	0.5	0.0
General life satisfaction	0.7	0.4
Memory compared to others	0.4	0.1
History of arthritis	0.8	0.1

Even though "don't know" response rates are low, they can't necessarily be ignored in analyses, as those responding this way may have different characteristics. One example is shown in table 4, where age-specific two year mortality rates for men are shown according to the presence or absence of a "don't know" response to any of the three items of the Rosow-Breslau physiphysical function index. Thus, for men, not having complete responses to any element of this function status inventory was associated with a clearly poorer prognosis. Similarly, refusing to take the memory test noted above seemed to have import for data quality. Table 5 shows "don't know" response rates according to participation in the memory test for any item in various categories. It is clear that refusing to participate was associated with a greater frequency of "don't know" responses.

Table 4
Two-year all-cause mortality rates (%) according to type of response to the Rosow-Breslau function status index: males; baseline survey

	Response			
	Complete		"Don't know"	
Age group (yrs)	N	Mort. rate	N	Mort. rate
65-74	797	4.8	29	13.8
75-84	448	12.9	24	33.3
85+	94	21.2	7	57.1

Table 5
Percent of subjects with any "don't know" responses according to participation in memory testing procedures

Item category	Participation in memory test yes	 no	
General health history	2.7%	5.7	*
Function status	14.6	22.8	*
Mood	3.1	7.1	*
Social support	3.3	5.7	

* - P<0.05

Finally, with respect to "don't know" responses, we performed multiple regression models to explore their correlates. To summarize briefly, these responses increased with age, were more frequent in women, and were generally unrelated to education. After controlling for age and sex, higher numbers of medical conditions, increased physical dysfunction and poorer memory test performance were all associated with more frequent "don't knows." Those with more self-perceived memory problems, sometimes know as metamemory, also had a higher frequency of "don't know" responses. However, since the rates of these responses were generally low and unstable among the item categories, these correlates rarely explained more than a few percent of the variance.

The other general measure of data quality was inconsistent responses. Within the baseline questionnaire we identified three duplicate items concerning subjective states, and when the responses were clearly divergent, these were scored as inconsistent for purposes of this analysis, and in the regression models discussed below, each individual is scored as having 0-3 inconsistent responses (IRs). Table 6 shows the mean numbers of inconsistent responses on the baseline survey, by age and sex. Interestingly, as in the "don't knows," the IR rate was generally not substantially related to educational attainment. Out of the possible three IRs, the average was about a third of an item per respondent. The table also shows that the rate increased with age in men but was flat in women. The reason for this disparity is unclear, but we are pursuing some possibilities.

Table 6
Mean number of inconsistent responses according to age and sex: baseline Iowa Survey.

	Age group (years) 65-74	 75-84	 85+
Men	0.30	0.32	0.53
Women	0.29	0.30	0.26

As shown in table 7, the number of IRs correlated significantly with a variety of a number of variables.

Table 7
Overall correlation of inconsistent responses with other study variables: baseline Iowa survey

Item or scale	Correlation coefficient
No. of major illnesses	0.06**
No. of minor illnesses/ symptoms	0.04*
Rosow-Breslau function index	0.06**
Depression symptoms scale (affect)	0.13***
Depression symptoms scale (somatic)	0.19***
Self-rated memory function scale	0.09***
Memory test score	-0.07***

* = p<0.05, ** = p<0.01, *** = p<0.001

Though it is not possible to describe each variable in detail, IR rates were positively correlated with the number of major and minor illnesses, higher levels of physical dysfunction and a higher number of both affective and somatic symptoms of depression. Also, at least in this bivariate analysis, more IRs were found among those with poorer self-rated memory function and poorer scores on the free recall memory test. It is important to note that in our data, these memory variables all show poorer function or performance with age cross-sectionally, and thus the interactions of these variables must always be considered. All of the correlations in table 7 are significant, though most are small in magnitude. In a series of regression models, after controlling for age, sex and the minimal effect of educational attainment, each of the variables remained significantly related to the rate of IRs.

Discussion

We can draw several at least tentative conclusions from these findings.

1. The rates of missing data ("don't knows" and refusals) are generally low on an item basis, as in many complex surveys, but when many are used in multivariate models, this becomes a substantial analytical problem. Further, based on cross-sectional studies, the "don't knows" and refusals have some different correlates, suggesting that they may represent different cognitive phenomena. It remains problematic whether the presence and rate of missing data, particularly the "don't knows," reflect only cognitive impairment or other factors on theoretical grounds, and more work is needed in this area.

2. At least in our health survey of the rural midwestern elderly, missing data items can be related to altered health states, and thus the routine exclusion of subjects with missing data in multivariate analyses may change study outcomes in important ways. In fact we have already had such an experience in one of our mortality analyses.

3. Both objective and subjective tests of memory performance can usefully be applied to population surveys of the elderly, both to describe the population distributions of these phenomena for their health and functional implications and to explore the mechanisms of altered validity of other study items. It should be noted, however, that many problems in survey accuracy have been described beside the inability to recall events, including possession of faulty information, telescoping of events, confabulation and deliberate lying (3). Not all of these activities are necessarily related to memory performance, and would not be expected to relate to such standardized measures. For example, a person not informed by her physician of a medical condition, or a functional activity that is untested cannot be accurately reported.

4. The rates of inconsistent responses within a survey, a standard measure of response reliability, may at least on intuitive grounds reflect to some extent cognitive impairment and have implications for data validity. However, rigorously evaluating this possibility also requires actual validation of responses with outside sources, a process currently underway.

In laboratory testing of memory function in the elderly, most investigators find a cross-sectional decline with increasing age. This was true for missing data rates in both sexes and for inconsistent response rates in men. However, in surveys which ask recall of actual events such as auto accidents, voting activity or previous items queried on previous surveys, a decline in accuracy with age does not always emerge. Several reasons for this discrepancy are possible. Older persons who are ill, clinically cognitively impaired or institutionalized may not often be included in such surveys. The definition or range of "elderly" may vary, and the number of "oldest old" participants uncertain. Most importantly, abstract cognitive testing may not totally reflect functional memory abilities in everyday life situations, perhaps in part because under actual living conditions certain elements of cognitive capacity are not tested and the environmental mediators of cognitive performance are not considered. Despite this, we found that our free recall memory test was significantly related to the rate of inconsistent responses, even in persons over 85 years old. This suggests that including objective cognitive tests in surveys of the elderly, if acceptable to respondents and adequate resources are available, may help provide a built-in assessment of data quality.

5. We also found that our reliability measures were related at least to some extent to self-rated memory items, independent of the memory test and general health status. These are easy to query and may hold some promise as an internal check on reliability. However, it is still controversial as to whether these items accurately reflect objectively tested memory function. One possible reason for the relation to self-rated memory lies in one of our other findings: the reliability measures also were associated with the affective and somatic symptoms of depression. These symptoms, not synonymous with clinical depression, may reflect lower levels of motivation or attention, yielding the results noted. Depression symptoms may be present due to the impact of physical disease, making the relationship ever more complex. However, brief measures of affect in surveys may in the future also serve as guides to data quality.

Intensive study of the elderly in population surveys has clearly uncovered new problems for survey quality, but also new opportunities to improve that quality.

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CHOOSING THE MOST APPROPRIATE FIELD APPROACH FOR OLDER POPULATIONS: THE CASE FOR MIXED-MODE SURVEYS

Sharon L. Tennstedt and John B. McKinlay
New England Research Institute

While there have been major improvements in data gathering techniques over several decades, the methods devised and tested to date derive from studies of generally younger populations. It is not clear whether these field methods are applicable, or even adaptable, to older populations.

There is, of course, no right and wrong way to do field work. All field approaches are useful, but some are more useful than others. The attributes of each method must be considered in relation to the study topic and objectives and the characteristics of the population to be surveyed, the latter a critical consideration in studies of older populations.

This paper provides an overview of the characteristics of older people which might influence their participation in a study. A discussion of traditional field approaches as they relate to these characteristics follows, which develops an argument for the use of mixed-mode approaches in studies of older people.

Social Circumstances and Health Characteristics of Older People Which Affect Field Approaches

Available sociodemographic data on persons classified as old point to one conclusion--the group is highly heterogeneous (Rosenwaike, 1985). This variation in characteristics has important implication for the selection of appropriate field methods to ensure adequate response rates and collection of high quality data. The majority of older people live in the commmunity and are in good health. However, when data for various age groups are analyzed, important differences emerge which have implications for how research should be conducted. The biggest differences generally occur at age 85 years and over.

This group of "oldest-old" is of great interest to researchers today. They also present the greatest challenge to researchers because their social and physical characteristics influence their willingness and/or ability to participate in research studies. Perhaps having the most potential impact on participation in research is the health and functional status of the oldest-old. A shift towards poorer health with increased age is evidenced in perceived health status, bed days, and limitations of activity in this community-based population. The latter showed the largest differences in relation to advanced age. For example, among people aged 65-74 years, 38 percent reported some limitation in activity, with 12 percent completely unable to perform their usual activity. In contrast, of people aged 85 and over 60 percent reported limitations in activity, with 22 percent completely unable to perform their usual activity.

Table 1 summarizes some pertinent national health statistics from the Supplement on Aging to the National Health Interview Survey (NCHS, 1986) which affect the feasibility of field approaches. Focussing on people over 75 years of age, more than four out of 10 people have hearing impairments, with between 40 and 60 percent experiencing difficulty even with a hearing aid. Approximately one out of every four people over the age of 85 years reports trouble with vision, with over 50 percent experiencing difficulty seeing even with glasses. Difficulty getting out of bed or a chair (regarded as a good indicator of limitation of activity) is reportedly a common experience among people over 85 years, with almost one in five reporting such trouble. The reporting of difficulty grasping small objects (such as a pen) ranges from 9.5% in those aged 65-74 years, to 14.5% of those over 85 years.

Further, there are gender differences for these limitations. Men are more likely than women across all age groups to have hearing impairments and further have been reported to be less inclined to use the telephone - important points if a telephone methodology is the mode of choice. Prevalence of visual impairments, on the other hand, is similar for both men and women. However, women report more physical limitations, especially as age increases. Therefore while there may be more very old women available for study, researchers must consider the specific nature of these impairments in order to facilitate their participation and achieve the desired gender ratio in the study sample.

These physical impairments obviously affect the success of the different field approaches. Rather than reflecting an unwillingness to respond, nonresponse may result from an inability to respond to an inappropriate field approach. In this situation culpability for failure must rest not with some "recalcitrant" respondent, as is usally assumed, but with the researcher, who may repeatedly employ the same inappropriate field approach (e.g. repeat mailings of a questionnaire to someone who cannot see well or cannot write, or unannounced field visits to subjects too impaired to answer the door).

Apart from functional status, some social characteristics of older people influence the success of different field approaches. The proportion of people living alone -- which is the situation of one out of two women over 85 years of age -- may affect the success of in-person interviewing in the community. From data presented by Lebowitz (1975), it appears that some 71% of people over 60 years of age in large cities are fearful for their personal safety, and therefore are likely to exhibit reluctance to permit strangers (e.g., field workers) to enter their homes to ask personal questions. In fact, recognizing the risk, many community groups and service agencies specifically advise their members and clients not to answer personal questions on the telephone or let strangers into their homes.

Clearly, these data indicate wide variation both within and across age groups. Field approaches and modes of data collection must accommodate such diversity in potential respondents' ability as well as willingness to participate in a research study. Without recognition of this point and appropriate adjustment of traditional field methods to facilitate participation, both the response rate and the data quality will be compromised.

Traditional Field Approaches: Advantages and Limitations

For a long time the face-to-face, or in-person, interview was thought to be the only way to obtain valid and reliable information. Even today there are some who regard it as the only approach. However, that situation seems to be changing quite rapidly for a number of reasons, cost being a primary one. Several developments relating to alternative field approaches (e.g., telephone interviewing and mailed questionnaire) have rendered them attractive when compared to in-person interviewing. When in-person interviewing became well-established in the 50's, only about 40-50 percent of the American public had telephones and, therefore, in-person interviewing was the optimal approach. Today, however, an estimated 95 percent have telephones, with older people just as likely as younger adults to have telephones, making this a very attractive mode of data gathering (Marcus and Crane, 1986). Even for the 20-30 percent of potential respondents who have unlisted telephone numbers, we have found that a letter requesting that they call us collect frequently generates a response and subsequent participation in the study.

Mailed questionnaires have also become feasible and attractive as a result of the improved and well-tested techniques developed, for example, by Dillman (1978, 1982). His Total Design Method (TDM) ensures acceptable response rates through use of a well-developed sequence of tested steps, and attention to details such as the formatting of questions, the length of the instrument, the weight and color of the paper, how inserts should be folded, the days on which mailings should occur, and so forth.

The advantages and limitations of the three major field approaches(in-person interviewing, telephone interviewing, and mailed questionnaire) have been reported by several researchers (Fowler, 1984; Kish, 1965; Hochstim, 1967; Siemiatycki, 1979, 1984a, 1984b; Groves and Kahn, 1979). Clearly the mailed questionnaire has distinct cost advantages over in-person interviewing, which is far and away the most expensive field approach. Telephone interviewing may be marginally more expensive, while in-person interviewing across a broad geographic area is prohibitively expensive. Larger sample sizes can be obtained cost-efficiently with mailed questionnaires and also with telephone interviews, while in-person interviewing generally permits only a relatively small group to be reached. Mailed questionnaires have well known disadvantages, however. Their response rates are usually quite low, the length of the interview must be brief, and only limited information can be obtained.

Data quality clearly varies by mode. For the mailed questionnaire, for example, one is never sure that the correct respondent completed the instrument or that the questions were comprehended. Furthermore, nothing can be done about item nonresponse which can be quite high. With in-person and telephone interviewing, however, one can check that the correct respondent is being addressed, there can be reasonable confidence that the question is comprehended and, when appropriate, prompts and some explanation can be provided. Further, well-trained interviewers, with appropriate monitoring, can minimize item non-response.

In this comparison, it appears that the telephone interview is generally superior to the other two modes, although some researchers claim that it may be more difficult to conduct with older people (Cannell et al, 1982; Massey et al, 1981; Thornberry and Massey, 1984; Herzog et al, 1983). While both the mailed questionnaire and the in-person interview have distinct advantages, they also have obvious disadvantages, which are not shared by the telephone interview.

The Promise of Mixed-Mode Field Approaches with Older Populations

What are the implications of these data for studies of older populations? In Table 2, it is clear that, even within a single study, what may be appropriate and acceptable to some respondents may be quite inappropriate and disagreeable to others. For example, it is appropriate to distribute mailed questionnaires to people who are hard of hearing, but unrealistic to undertake telephone interviews. However, it may be possible to conduct an in-person interview in this situation. Conversely, the sight-impaired can complete in-person and telephone interviews, but cannot be expected to complete a mailed questionnaire without assistance. People with major speech/language pathology (e.g., as a result of stroke) cannot easily undertake a telephone interview, but may complete a mailed questionnaire and, depending on the skill of the interviewer, may complete an in-person interview. Paraplegics and arthritics may have difficulty with a mailed questionnaire, but be able to complete a telephone or in-person interview. In addition, fear of strangers and concern for personal safety may rule out an in-person interview with some respondents, but make mailed questionnaire and telephone interviews quite acceptable.

Therefore, perhaps among the elderly, more than any other demographic group, there is a need for flexibility in research methods and the case for mixed-mode surveys i.e., studies which attempt to obtain the same information from an identified population through different field approaches. Mixed-mode surveys are usually viewed as a means of simply achieving higher response rates by getting responses from people who otherwise will not respond (Brambilla and McKinlay, 1986). However, they may be particularly useful in studies of older people who experience the types of impairments and limitations previously described. Again, they may be a means of getting responses from people who simply cannot respond. Mixed-mode approaches are not only a desirable method for improving response rates, therefore, but in community-based studies of the oldest old in particular, they may be essential if reliable data are to be obtained (Herzog et al, 1983).

Most mixed-mode surveys usually start with either mailed questionnaires or telephone interviews (Hochstim, 1967; Hochstim and Athanasopoulos, 1970; Goudy, 1978; Siemiatycki, 1979; Brambilla and McKinlay, 1987a). Follow-up of nonrespondents usually involves the other of these two, an in-person interview, or a combination of approaches.

Compared with in-person interview surveys, mixed-mode designs cost less but have produced the same high response rates (Hochstim, 1967; Siemiatycki, 1979). Compared with surveys by either mail or telephone alone, the mixed-mode approach has produced higher response rates and, more important, less socioeconomically biased responses (Hochstim and Athanasopoulos, 1970; Siemiatycki and Campbell, 1984; Brambilla and McKinlay, 1987a).

While mixed-mode surveys offer considerable promise in studies of older populations, not surprisingly they have their disadvantages and limitations. Our research has been addressing these issues, particularly issues of cost, missing data, and response validity, as discussed briefly below.

Cost: Follow-up constitutes work in excess of effort normally expended in single-mode mail or telephone surveys, so mixed-mode surveys are always more expensive than surveys by the initial mode alone, but less expensive than using the in-person mode alone (Hochstim, 1967; Siemiatycki, 1979).

Missing Data: Aside from a few well-known items (e.g., household income), item nonresponse is most frequent on mailed questionnaires (Hochstim, 1967; O'Toole et al, 1986; Brambilla and McKinlay, 1987b). Thus, mixed-mode surveys that include this mode may produce somewhat higher levels of missing data. Much of the problem is apparently caused by inadvertent respondent error, which can be reduced through careful instrument design (Brambilla and McKinlay, 1987c). Data missing for other reasons are of greater concern. The propensity for item nonresponse can vary with respondent characteristics, especially on mailed questionnaires (Brock et al, 1986; Brambilla and McKinlay, 1987b). These data are clearly not missing at random and can bias survey results (Rubin, 1976). We have found in health related surveys that item non-response is related to health status, although estimates of bias are not yet available and more work is needed in this area.

Response Validity: The issue of validity arises from the frequently observed variation among modes in response to some items in mixed-mode surveys (Brambilla and McKinlay, 1987a; Siemiatycki and Campbell, 1984; Hochstim and Athanasopoulos, 1970). Telephone and in-person interviews may be more likely than mailed questionnaires to suffer from biased recall of, for example, a recent visit with a physician (Siemiatycki et al, 1984), responses to personally sensitive questions, or those with socially desirable answers, such as attitudes toward abortion (see Frey, 1983, for review). Frey notes, however, that these problems have rarely biased results sufficiently to compromise the inferences from a mixed-mode survey. In addition, mode-dependent response variation can be minimized through sensitive interviewing and careful question design (Komaki and Goltz, 1987). Finally, some of this variation is actually caused by factors that are confounded with mode, such as characteristics of early vs. late respondents, rather than the modes themselves (Brambilla et al, 1987). This implies that responses to the initial mode are a biased sample of the population, rather than indicating mode-dependent variation in the validity of survey respones.

Many researchers are understandably reluctant to mix different approaches. Some prefer to remain with one approach with which they are familiar, despite limited return. The only potential advantage to single-mode surveys is uniformity of responses to specific questions. However, even this advantage is minimized with careful design of question presentation.

Proxy Interviews

The final comments relate to the use of proxy interviewing in studies of older people. While there are both varying opinions and evidence on the effect of proxy interviewing on data quality, when studying old people, and especially the oldest-old, it may be the alternative to no data at all. Given severe impairments, physical and/or cognitive, an older individual may simply be unable to participate. Therefore, where it has been thought that proxy respondents can constitute a major source of bias in health surveys, it may very well be that not using proxies in studies of the oldest-old may be a source of bias.

The criteria for selection of an appropriate proxy are not addressed here. However, researchers should be aware that the most appropriate proxy is often old, if not very old, as well. Therefore, their ability to participate in a study, as related to their own limitations, must be considered - strengthening the argument for mixed-mode surveys,

In summary, it is not our intention to argue for one ideal way of conducting social research with older populations. Rather, the essential message in this paper is the need for flexibility . While all field approaches are useful, some appear more useful than others, depending on the topic and objective of the study and characteristics of the population under investigation. We view mixed-mode surveys as particularly promising with older populations, although their limitations are well recognized. Certainly, in-person interviews can no longer be considered the "gold standard," may indeed be a luxury during economically stringent times for sociomedical research, and finally may not be appropriate for, or faciliate, participation by older people. Mixed-mode surveys permit flexibility in field approach which can facilitate study participation, thereby enhancing both response rates and data quality.

TABLE 1

NATIONAL ESTIMATES OF
PHYSICAL LIMITATIONS
BY AGE AND SEX

LIMITATION	AGE			TOTAL
	65-74	75-84	85+	
• Hearing	23.0	32.7	48.4	27.8
Difficulty even w/ hearing aide	33.1	45.0	62.5	38.9
• Vision	9.5	16.0	26.8	12.8
Difficulty even w/ glasses	24.7	39.3	52.6	31.1
• Difficulty getting out of bed or chair	6.1	9.2	19.3	8.0
• Difficulty grasping small objects	9.5	12.4	14.5	10.7

Source: National Health Interview Survey, Supplement on Aging, 1984.

TABLE 2

ADVANTAGES AND LIMITATIONS OF
THREE MAJOR FIELD APPROACHES
GIVEN THE IMPAIRMENT AND ATTITUDES
OF OLDER PEOPLE

	In-Person Interview	Telephone Interview	Mail Questionnaire
Hard of Hearing (Deaf)	P	I	A
Sight Impaired (Blind)	A	A	I
Speech Language Pathology	P	I	A
Arthritis/Tremors/ Paraplegia	A	A	I
Fear of Strangers	I	A	A

A = Appropriate
I = Inappropriate
P = Possible

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MEASUREMENT ERROR IN INTERVIEWS WITH ELDERLY RESPONDENTS

by Willard L. Rodgers and A. Regula Herzog, The University of Michigan

Introduction

The Survey of Michigan Generations is a methodological study funded by the National Institute on Aging. Its primary objective is to assess the prevalence and the consequences of several types of non-sampling measurement error, with a focus on the elderly population. Among the sources of non-sampling error that we have examined are unit and item non-response and various types of reporting errors, including mode effects, interviewer effects, question wording and response scale effects, and context effects. For each such source, our goals are to assess their frequency and to examine the consequences of these errors with respect to univariate distributions (i.e., means and variances) as well as estimates of bivariate and multivariate statistics. Moreover, based on the increasing proportion of older persons with physical and mental health limitations, memory losses, and presumed lower motivation, it is often assumed that these error sources are more serious for older than for younger respondents. Evidence for such age trends in the general population is, however, sparse, and a major purpose of this study is to examine this issue.

Methods

The design of the study is described in more detail elsewhere (Rodgers and Herzog, 1987). In brief, the target population consisted of all adults living in households in the Detroit metropolitan area in 1984. Sampled households were screened to determine if any member was age 60 or older; the remaining households were selected at a lower rate. One or two members of the selected households were randomly designated as respondents, and interviews lasting an average of about 90 minutes were obtained with a total of 1,491 respondents, 1,016 of whom were age 60 or older.

In addition to the survey data, additional information was obtained from a variety of sources: administrative data (e.g., voting records for three recent elections), census data for the blocks on which sampled households were located, distances measured from maps to neighborhood facilities, and interviewer observations about the households and designated respondents.

An additional feature of the design that is central to this paper is that if the randomly designated respondent in a household was married (or living with someone), the spouse was also designated as a second respondent in that household. Moreover, the married respondents were asked a set of questions about their spouses, parallel to questions about themselves, so that if both members of a married couple completed interviews, self- and proxy-reports are available for these characteristics.

Findings

Overview of previously reported findings

Space limitations do not allow more than a brief overview of some findings based on comparisons between survey measures and data from external sources; these findings are described in two papers (Rodgers and Herzog, 1987a, 1987b). We have found frequent, and often substantial, discrepancies between survey-reports and data from external sources (i.e., administrative records, maps, etc.) on a variety of variables, including whether or not the respondents voted in recent elections, the assessed value of their homes, and distances to neighborhood facilities (e.g., the nearest drug store). Moreover, these discrepancies do not appear to be random, as is often assumed in the absence of external criteria against which to assess the self-reports. On most of the variables examined, there is a significant bias in the self-reports relative to the external records: for example, respondents tended to over-report voting in each of three recent elections and the amount of property taxes they paid in the preceding year. Even more serious for many types of analysis is the finding that the discrepancies are not independent of other substantive variables that are typically included in multivariate analyses, indicating that sample estimates of bivariate and multivariate parameters derived from survey data are often subject to bias.

On the other hand, we have found no evidence to support the notion that measurement errors are more frequent, or their consequences more serious, for data from older respondents than for data from other age groups. While there are significant age differences for some variables, these are favorable sometimes to the older, sometimes to the younger respondents. At the same time it is important to recognize the limits to the generalizations we can draw from the present study. "Older" respondents are here defined as those age 60 and older, with distinctions drawn between those under age 60, those 60 to 69, and those 70 or older. Only a small proportion are in the "oldest old" age group (age 85 and older), where the problems of non-response and lower quality data might be expected to be most serious. Moreover, the data obviously exclude non-respondents, meaning that self-selection may operate to remove those with the most serious health and motivational problems.

Non-response as a source of measurement error

In the remainder of this paper, our focus is on data available from married respondents because only for these respondents were proxy- as well as self-reported data requested, thereby permitting comparisons of respondents and non-respondents and assessments of the quality of the self- and proxy-reports that would not be possible for non-married respondents. A total of 1494 persons who were married (or quasi-married) and living with their spouses were selected as eligible respondents. That is, given the sample design, 747 couples were selected. The response rate is shown in Table 1. In somewhat less than half of the eligible households, both members of the selected couple participated in the study (these will be referred to as "two-respondent households"), and in another fifth or so of the households just one member of the couple participated ("one-respondent households"), while in the remaining 30 percent of the households neither person was interviewed ("zero-respondent households"). Put from the perspective of the individual respondent, we obtained self-responses from 59 percent of those selected, proxy-responses from another 11 percent, and neither type of response from 30 percent.

Differences between one- and two-respondent households. The importance of non-response as a source of measurement error is conditional on (1) the frequency of non-response, and (2) whether non-respondents differ from respondents on characteristics that are related to substantive variables of importance to the study. The frequency of non-response in this study is clearly high and therefore a potential source of measurement error: more than 40 percent of the designated married individuals did not grant interviews.

To get at the issue of whether non-respondents differ from respondents, data about the 710 respondents and the 166 non-respondents for whom we do have reports from spouses may be examined. It is not obvious, of course, that the 166 non-respondents for whom we have proxy-reports adequately represent the total set of 618 married non-respondents. It seems likely that observed differences would underestimate the differences between respondents and all non-respondents, since one-respondent households are probably intermediate in most respects between two- and zero-respondent households. Comparisons of reports about one- and two-respondent households were made for a total of 35 items, and statistically significant differences ($p < .05$) were found for 13 of them; these differences are shown in Table 2. One-respondent households had incomes almost $6,000 lower, on the average, than did two-respondent households. Moreover, the sources of income differ: the one-respondent households were less likely to have income from savings and investments or from the husband's job, but more likely to have income from disability payments, welfare, or charity. Also noteworthy is the fact that the spouses of non-respondents rated their household incomes less highly and were more worried about using up their savings and investments than were the spouses of respondents. (These latter two items are not shown in Table 2 since they are subjective ratings rather than descriptions of the household.)

The houses in which the one-respondent households lived were smaller than those of the two-respondent households: they had fewer total rooms and fewer bathrooms. Moreover, they were less likely to heat their homes with natural gas, the fuel used by more than ninety percent of the respondents. For the subset of couples who owned their homes, the average value of the homes of one-respondent households was about $9,000 lower than that for two-respondent households. One-respondent households had moved into their current residence an average of 23 months before the two-respondent households. Finally, one-respondent households lived closer to neighborhood facilities than did two-respondent households.

Differences in reports by spouses about respondents and non-respondents. In addition to the questions about household and neighborhood characteristics that apply to all members of a household (though often, perhaps, perceived and evaluated differently by each person), married respondents were also asked a set of seventeen questions specifically about their spouses. These items included a factual item (date of birth), the frequency of certain activities, evaluations of their overall and functional health, and their perceptions of how satisfied the spouse was with three domains of life.

In a subsequent section we consider the quality of such proxy-reports relative to self-reports, but in this section we ask whether there are mean differences between respondents and non-respondents on any of these measures. Statistically significant ($p<.05$) differences were found on four of these items, as listed in Table 3. Also included as the first entry in Table 3 is the sex of the respondents and non-respondents, on which one of the largest differences between respondents and non-respondents is observed: more than three out of four of the non-respondents whose spouses did participate were males. Compared to respondents, non-respondents were described by their spouses as having greater difficulty in getting around the house and less satisfied with their friends. The non-respondents were also less likely to have voted in at least two of three recent elections. The greater frequency of mobility problems reported for non-respondents could account at least in part for the other differences as well as for the reluctance or inability of some persons to complete the interview. Mobility problems are more frequent among older people, and non-respondents are an average of 21 months older than the respondents according to their spouses. (The age difference is not shown in Table 4 because it is not statistically significant at the .05 level ($t=1.69$, $p=.09$).)

The usefulness of data from proxy reporters

The data shown in the preceding tables indicate that there are differences between respondents and non-respondents, both at the individual and the household level. These differences are problematic because they call into question the representativeness of the respondents with respect to the population from which the original sample was selected. Non-response is a source of measurement error, and we have seen evidence that for some variables this type of error is systematic, introducing biases into the univariate distributions of these variables. Since we also observe that the elderly are over-represented among non-respondents, this type of measurement error may be particularly important in surveys of elderly populations.

One survey practice that may be useful in reducing the impact of non-response is the acceptance of proxy-reporters: someone else who knows the sampled individual, generally someone who is a member of the same household, is asked questions about that person, either as a method of reducing survey costs or explicitly as a method of reducing the non-response rate. This practice may introduce problems of its own, however, if the accuracy of proxy-reports is lower than the accuracy of self-reports.

The appropriateness of using information from proxies is an issue that has not been adequately resolved. Moore (1985) has reviewed the literature on this issue. He points out the wide range of current practice, even within a single agency, the U.S. Census Bureau. For example, in the Current Population Survey, a single informant is selected for each sampled household, and that informant answers not only questions about the household and his or her own labor force participation and other characteristics, but also about the characteristics of other members of the household. In the National Crime Survey, a single informant supplies information about the household as a whole, but separate interviews are sought with each household member to obtain information about individual victimization. In the Health Interview Survey, an attempt is made to include as many as possible of the household members in a group interview. For most surveys conducted at the Survey Research Center, on the other hand, proxy-interviews are not accepted; if the designated respondent in a sample household refuses or is unable to be interviewed, this is a non-response.

The reluctance of many survey researchers to accept the use of proxies is based on the assumption that many types of information, especially attitudes and other subjective states, can only be provided by the targeted individuals. As Moore points out in his review, evidence on the truth of this assumption is sparse. In many studies it is impossible to separate the effects of proxy-reporting from self-selection in the distinction between self- and proxy-reporters; and when differences are found, rarely are outside criteria available by which to distinguish which (if either) type of report is the more accurate.

The design of the present study allows us to compare self- and proxy-reports for a set of items, albeit only for a rather small number of married respondents: those in two-respondent households, for whom both proxy- and self-reports are available on a set of characteristics. Moreover, for a subset of those characteristics information is also available from another source, allowing both self- and proxy-reports to be compared to a criterion.

Statistically significant ($p<.05$) differences in the means of the proxy- and self-reports were found for eight of the seventeen personal characteristics for which proxy reports were obtained. These are listed in Table 4, which shows the means for husbands and wives separately since in two cases the proxy-effect is different across the sexes. According to the proxy reports, the respondents saw a doctor an average of 2.09 times in the preceding twelve months, whereas by their own count they did so just 1.86 times, a difference of almost a quarter of a visit per year. On the other hand, the proxy-reports indicate that the respondents visited with friends less often than did the self-reports.

With respect to the functional health of the respondents, the proxy-reports indicate that respondents had more difficulty in getting around the house, and less difficulty in remembering things, than did their self-reports. (The latter difference holds only for women; wives' reports on their husbands' memory indicate at least as frequent problems as do the husbands' self-reports.)

It is with respect to evaluative items that we might be most reluctant to accept proxy-reports as a substitute for self-reports, and Table 4 indicates that there are significant differences between proxy- and self-reports on satisfaction with each of three domains of life. In each case, the spouses report lower average levels of satisfaction than do the respondents in describing themselves. Moreover, respondents (especially women) also report that their spouses are more frequently depressed than do the spouses.

Quality of spouse data: Validity estimates. From Table 4 we have seen that there are statistically significant, and substantively important, differences in the distributions of self- and proxy-reports on a large proportion of the variables examined. This indicates that the decision to use proxy data should not be made casually, but by itself does not tell us whether the proxy-reports are either worse or better than self-reports. Moreover, the data in Table 4 tell us nothing about the impact of proxy data on measures of bivariate or multivariate relationships. Even if there were a systematic bias in proxy-reports, this might have no effect on measures of association; indeed, if there were less random error in proxy-reports than in self-reports, measures of association based on proxy data could be more accurate than measures based on self-reports.

As an initial step in evaluating the validity of proxy- and self-reports, we posit the simple measurement model shown in Figure 1. In the middle, represented by squares, are four measures as obtained from a married couple. X_1 is the husband's report on himself, and is modeled as influenced by his level on the concept — represented by the upper circle on the left — and by a method factor that influences how the husband uses the response scale — represented by the upper circle on the right. X_2 is the wife's report on the husband, and so is influenced by the same concept but also by the wife's response factor, the lower circle on the right. X_3 and X_4, similarly, are the reports of the two respondents about the wife. The small number of observed variables — four — requires that some strong, and perhaps dubious, assumptions be imposed in order that the model in this figure be identified. These assumptions include symmetry in the factor loadings for husbands and wives, and the independence of the method factors for husbands and wives.

Estimates of the parameters of this model are shown for each of sixteen characteristics in Table 5. The first two columns of numbers are labelled the validity coefficients for the self- and proxy-reports, and correspond to the parameters labelled λ_1 and λ_2 in Figure 1. In general, the two estimates are similar in size; across the set of items, the average values are almost identical. On some items and sets of items, it appears that proxy-reports are less valid than self-reports, but the reverse also appears to be true for other items. Overall, there is little basis for rejecting the use of proxy-reports, since they have been not been shown to be less valid indicators of the respondent characteristics.

At the same time, however, it must be kept in mind that the validity estimates just presented are based on a very small measurement model, with some questionable assumptions required for identification. In a more complete model, with a total of 29 observed variables, eight concepts, and six method factors, we estimated that the validities for proxy-reports of subjective measures such as those shown here were considerably smaller than self-reports (Rodgers, Herzog, and Andrews, 1987).

Finally, as mentioned earlier, outside measures were obtained for some of the characteristics for which both self- and proxy-reports were also obtained. The correlations of each type of report with the various criterion variables are shown in Table 6. Only two of the differences attain statistical significance ($p<.05$): those for measures of mobility and for date of birth. Both of these statistically significant differences favor the self-reports over the proxy-reports, but the overall pattern does not suggest substantial differences in the quality of these two types of report. Moreover, the quality of the outside criteria can also be questioned, especially those based on interviewer observations only.

Correlates of discrepancies between spouses. Regardless of their agreement with outside criteria, discrepancies between self- and proxy-reports indicate errors in at least one (and possibly both) of those reports. In our final analysis, for each respondent we have aggregated the discrepancies between these two types of reports (ignoring the direction of the discrepancies) across all seventeen characteristics measured in both ways, and then examined the correlations of this index with characteristics of the respondents and the proxies: their race, age, and education. We found no appreciable relationship between the discrepancy index and the age of the respondents or their spouses ($r=.004$ and $.010$, respectively); therefore there is no indication that the quality of either type of report is worse for older than for younger respondents. There was, however, a significant negative relationship to the education of both types of respondent (for the respondent's education, $r=-.234$; for the proxy's education, $r=-.191$). That is, there is more agreement between spouses who have more education in their reports about the individual characteristics of each other. This pattern makes the lack of any relationship to age even more noteworthy, since educational attainment declines with age in the current population. Other things being equal, therefore, one would expect the older respondents to disagree with their spouses more often than do younger respondents. There is also a significant relationship to race, with non-white respondents agreeing less with their spouses than white respondents ($r=.169$).

Conclusions

The data from the Study of Michigan Generations, as described in this and previous papers, are not overly reassuring with respect to the quality of survey data. Differences between non-respondents and respondents are an important source of measurement error. Moreover, there are frequent, and often sizable, discrepancies between survey measures and outside criteria, and as seen in this paper, between self- and proxy-reports. These discrepancies, moreover, are not randomly distributed, and often may introduce biases into univariate distributions and into measures of bivariate and multivariate relationships. While this message is not a new one, it is an important one, reminding us of the importance of renewing our efforts to improve our methods of data collection and to increase our understanding of measurement errors, where we cannot eliminate them, so that they can be properly taken into account in the estimation of population parameters. One method to improve the non-response problem may be to make increased use of proxy-respondents, both to obtain at least some information about non-respondents and as an additional source of information that is useful in assessing and enhancing the quality of self-reported data.

On the other hand, the data from our study suggest rather clearly that the quality of data from older respondents — at least those who are living in households and are willing and able to participate in a survey — is no worse than data from younger respondents.

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Table 1: Response Distribution by Married Individuals and their Spouses

Response	Number	Percent
Individual and spouse both responded	710	47.5%
Individual responded, spouse did not	166	11.1
Spouse responded, individual did not	166	11.1
Neither individual nor spouse responded	452	30.3
Total	1494	100.0%

Table 2: Differences in Household and Neighborhood Characteristics as Reported by Married Respondents in One- and Two-Respondent Households

Item	Type of Household		Difference	Prob.
	Two-R	One-R		
Family income	$33837	$28087	-$5750	.007
Percent reporting income from:				
Investments	56.3%	43.5%	−12.8%	.004
Husband's job	79.4%	67.1%	−12.3%	.001
Disability	3.5%	10.3%	+6.8%	.000
Welfare	5.9%	11.7%	+5.8%	.009
Charity	0.2%	1.9%	+1.7%	.008
# rooms	6.10	5.75	−.35	.006
# bathrooms	1.69	1.45	−.24	.000
Heat with gas	93.9%	87.5%	−6.3%	.005
House value	$58217	$49322	-$8895	.006
Date moved*	890	867	−23	.032
Distances (in miles) to nearest:				
Drugstore	1.39	1.13	−.27	.034
Grocery store	1.62	1.32	−.30	.027

* Number of months after December, 1899.

Table 3: Differences in Characteristics of Selected Individuals who Did and Did Not Respond, as Reported by their Spouses

Item	Respondent?		Difference	Prob.
	Yes	No		
Sex: Male	49.7%	77.4%	+27.7%	.000
Difficulty in mobility	1.17	1.29	+.12	.026
Satisfaction with friends	5.61	5.30	−.31	.009
Vote in 1980	72.4%	62.7%	−9.7%	.016
Vote in 1982	62.8%	50.3%	−12.5%	.005

Table 4: Differences between Self- and Spouse-Reports on Characteristics of Married Respondents

Variable	Husband		Wife		Proxy Effect	Inter-action*
	Self-Report	Spouse Report	Self-Report	Spouse Report		
Frequency of doctor visits	1.50	1.68	2.21	2.51	+.24	–
How often see friends	4.75	4.36	4.64	4.56	−.24	–
Difficulty in mobility	1.10	1.15	1.11	1.20	+.07	–
Difficulty in memory	1.66	1.74	1.84	1.47	−.15	−.44
Satisfaction with house	5.72	5.45	5.51	5.24	−.27	–
Satisfaction with friends	5.98	5.62	6.08	5.74	−.35	–
Satisfaction with life	5.91	5.41	5.89	5.57	−.41	–
How often depressed**	1.95	2.40	2.19	2.40	+.34	+.23

* Difference in proxy-effects for husbands and wives (shown only if statistically significant: $p < .05$).
** Item scoring reversed.

Table 5: Correlations of reports about self and spouse by Husbands and Wives

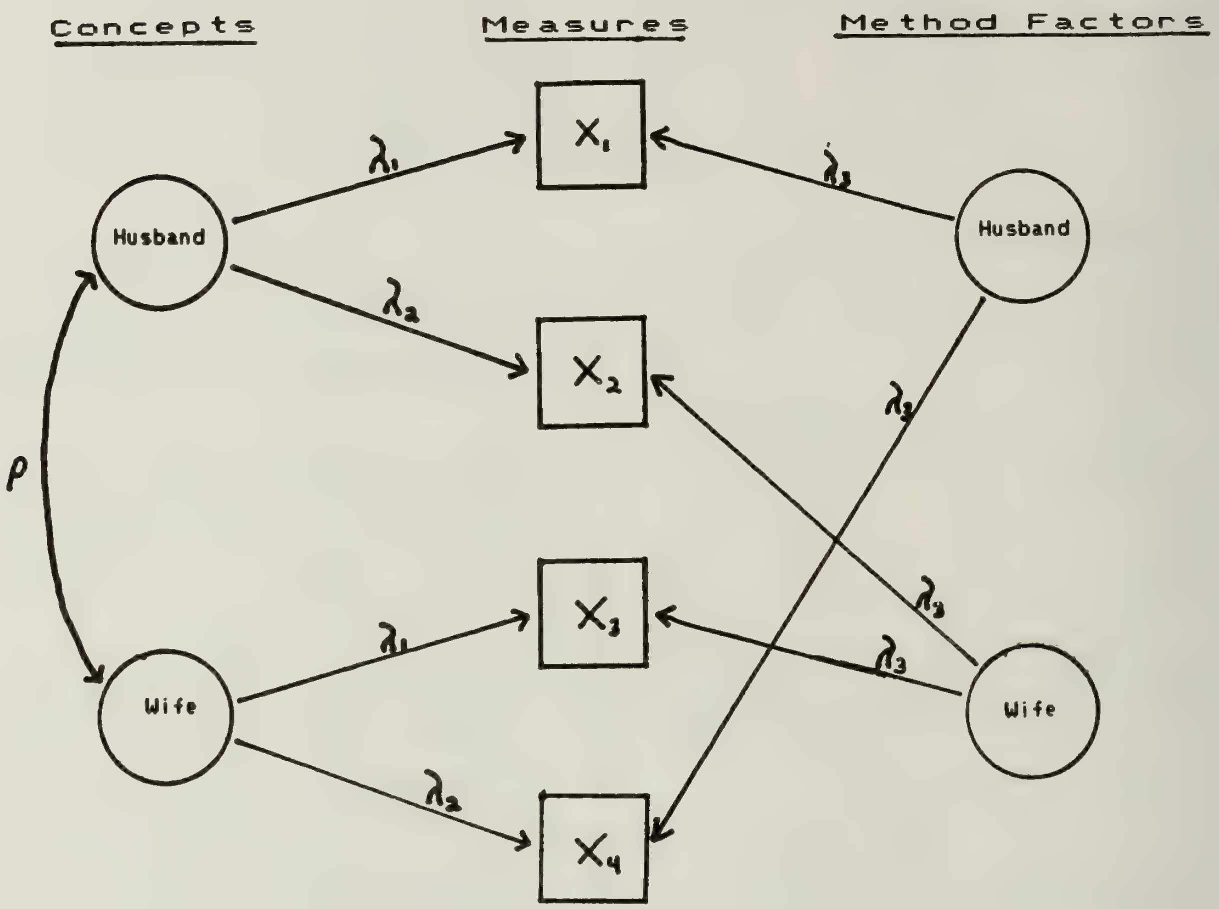
Variable	Validity Coeff.		Method Coeff.	Spouse Corr.
	Self	Proxy		
Frequency of behaviors:				
Doctor visits	0.828	0.808	0.215	0.061
Religious services	0.939	0.933	0.252	0.832
Visit friends	0.759	0.659	0.339	0.516
Average	0.843	0.809	0.273	0.503
Functional health:				
Vision	0.375	0.796	0.205	0.249
Mobility	0.628	0.959	0.107	0.294
Memory	1.104	0.309	0.321	0.115
Average	0.554	0.773	0.191	0.184
Subjective measures:				
Rate health	0.616	0.856	0.139	0.562
How often depressed	0.448	0.734	0.228	0.583
Satisfaction with house	0.747	0.679	0.439	0.770
Satisfaction with friends	0.420	0.378	0.457	0.691
Satisfaction with life	0.464	0.526	0.451	1.047
Average	0.554	0.638	0.359	0.722
Miscellaneous:				
Birthdate	0.998	0.995	0.001	0.957
Have job	0.878	0.895	0.000	0.478
Vote in 1980	0.833	0.869	0.310	0.575
Vote in 1982	0.856	0.754	0.375	0.761
Vote in 1983	0.816	0.741	0.422	0.824
Average	0.880	0.853	0.282	0.729
Overall average	0.728	0.750	0.285	0.581

Table 6: Correlations of Self- and Proxy-Reports
with External Records or Interviewer Reports

Variable	Self-Report	Proxy-Report
Functional health:		
Mobility		
Interviewer	0.690	0.615*
Memory		
Test	0.120	0.140
Interviewer	0.170	0.140
Vision		
Test	0.304	0.305
Interviewer	0.289	0.264
Hearing		
Interviewer	0.288	0.361
Birthdate		
Voting records	0.999	0.991*
Driver's license	0.998	0.990*
Voting (vs. records):		
1980	0.655	0.668
1982	0.648	0.578
1983	0.376	0.380
Average:	0.503	0.494

* Difference in correlations for self- and proxy-reports is statistically significant ($p<.05$).

Figure 1: Measurement Model



Session Z

Data Needs for Health Policy: Morbidity and Mortality

DATA FOR AN AGING POPULATION

ANALYSIS OF SURGICAL MORTALITY WITHIN THE MEDICAL CARE SYSTEM OF THE VETERANS ADMINISTRATION (VA)

Chester Davis and Dean Bross, Veterans Administration

Introduction

The Veterans' Administration Health Care Amendments of 1985 require that the VA's Quality Assurance Program evaluate mortality and morbidity rates for each surgical procedure performed in the Department of Medicine and Surgery. Specifically, national mortality rates for each surgical procedure performed by the VA must be reported. Rates for cardiac surgery, heart and renal transplantation in each VA medical center performing these operations also must be reported. In preparing the report the department must determine whether VA rates, adjusted for patient age, disease severity, and complications, deviate significantly from "...prevailing national mortality and morbidity standards for similar procedures...." If VA rates differ from national standards then the department must determine whether these differences are the result of deficiencies in the quality of VA medical care. The department is required to make recommendations, based upon the findings of this analysis, to the VA Administrator. These recommendations address the need for additional resources or changes in policies which would improve the quality of surgical care. This spring the department submitted an interim report to the Congress which described the results of the first phase of this effort. In addition to providing a descriptive analysis of surgical care in the VA, the report detailed the department's plans for testing a information system which can provide the required quantitative data for policy analysis.

In this presentation we will describe some of the major problems encountered when national data files are used to evaluate VA surgical mortality experience as specified by this law. We will describe the establishment of surgical risk groups and mortality rate thresholds. We will discuss the method of extrapolating data from the National Hospital Discharge Survey (NHDS) so that the nonfederal hospital surgical mortality experience, (excluding cardiac surgery, heart and renal transplantation), could be compared to that of the VA.

One major requirement of the law is that national mortality and morbidity standards must be used to judge the quality of VA surgical care. The department determined that national or professionally accepted standards for surgical mortality and morbidity rates did not exist. In reviewing the surgical literature, we discovered that there are many definitions of a surgical death that is, death resulting from surgery. For example, some authors examined deaths that occurred within 24 hours of surgery while others looked at deaths that occurred within 60 days of surgery. For the purpose of monitoring the program the Surgery Service of the department defines a surgical death as a death occurring within 30 days of surgery. We also found that there were many different methods for measuring severity of illness, but none of them were adequate for this task. In addition the comparison of VA surgical outcomes to those of the non-VA hospital sector requires that differences between these populations be taken into account.

The population served by the VA is unusual in that it is mostly male and its age distribution reflects the manpower needs of the military during periods of conflict. A large segment of the veteran population served during World War II and the Korean War which encompasses the age groups 50-59 and 60-64. The population is skewed toward the older age group, with 17% of male veterans being over the age of 65. This graying of the veteran population is likely to continue if there are no major military conflicts in the future. The population of veterans treated in VA medical centers has an even more unusual distribution. Some factors which play a major role in determining the VA patient population is the increased need for hospital care by the aging population and the eligibility and priority rules contained in VA legislation. As a result, the VA serves a high proportion of low income veterans and those whose condition is related to their military service. The VA had approximately one million hospital discharges in fiscal year 1985. About 24% of these discharges had surgery during their hospital stay, and less than 15% were younger than age 44. Females comprise less than two percent of the VA surgical population.

Data Sources

The data for the Congressional report were developed from the VA Patient Treatment File (PTF) and the National Hospital Discharge Survey (NHDS). The PTF and the NHDS are independent data collections systems that capture gross data on the output of the nation's hospitals, both VA and non-VA. They present a 'snapshot' view of various hospital activities during a year, surgery being only one of several components. These systems were not designed to provide data which would permit a complete description of surgical care or permit a comprehensive assessment of the quality of surgical care provided in VA medical centers or in the non-VA hospital sector. These were, however, the only data systems available that had some of the necessary patient based data required for this report.

VA Patient Treatment File (PTF)

The Patient Treatment File (PTF) is an administrative computerized data base. The data in this file were abstracted from the medical records of all inpatients discharged from VA Medical Centers during a fiscal year. The PTF contains one record for each episode of inpatient care. Data in each of these records includes: patient age, sex, veteran eligibility status, medical diagnoses treated, surgical procedures performed, length of stay, and whether the patient expired as a hospital inpatient. In any given PTF record for a surgical patient a maximum of five ICD-9-CM procedure codes may have been abstracted for each time the patient entered an operating room (O.R.). The PTF can accommodate a maximum of ten trips to the O.R. for each surgical patient. Frequency distributions of surgical procedures performed during the fiscal year revealed that some procedures were performed more frequently than others. When we examined the first surgical code abstracted for the PTF, the "primary surgical code", we found that only 23% (505) procedures were associated with at least one inpatient death, and just five percent (119) of the procedures could be associated with at least 10 deaths.

It is very important to note that the PTF does not contain data on the cause of death. A causal relationship between surgery and death cannot be not imputed from data in these abstracts. Also, it should be readily apparent that these data do not suggest what kinds of inferences can be made about the quality of surgical care provided without applying the expert judgment of surgeons who have experience and knowledge about the variety of disciplines within the field.

The PTF does not contain information on patients who might have died at home or in a non-VA hospital. As a result, statistics on mortality associated with some surgical procedures may be underestimated. By the same token, the PTF does not capture sufficient information on the patient's health status upon admission, or his health status just prior to the conduct of surgery to permit appropriate statistical adjustments. The importance here is that a veteran may require surgical procedures on an emergence basis and the likelihood of survival may be significantly affected by the patient's health status.

Surgical Tracking Procedures

In view of the large number of surgical procedures performed in the VA system the department's task force on mortality and morbidity decided to select a set of 50 ICD-9-CM surgical procedures that would be representative of the VA surgical workload from perspective of (1) the complexity of the operations, (2) types of surgical specialities within the Department, (3) mortality experience with procedures, (4) procedures expected to be performed on an adult male population, and (5) the number of patients discharged who had a given procedure during their hospitalization. The surgical procedures that were identified were called tracking procedures. Examples of these tracking procedures include craniotomy, total pancreatectomy, amputation above the knee, sigmoidectomy, total cholecystectomy, transurethral prostatectomy, and hip replacement. These tracking procedures when aggregated represent about 25% (61,436) of all patients who had surgery and who were discharged in FY 1985. Slightly more than 26% (1,629) of all patients who expired as hospital inpatients within 30 days of surgery had one of these tracking procedures performed during their stay. The crude mortality rate for all tracking procedures combined was 2.6%, and this was nearly the same as the rate for all patients who had surgery, 2.5%.

Surgical Risk Groups and Mortality Rate Thresholds

These tracking procedures were assigned to one of 21 procedure groups by the task force. Each of these groups had at least one and a maximum of seven tracking procedures assigned to it. These procedure groups were in turn assigned by the task force to one of four risk groups: High, Medium High, Medium Low, and Low risk. The four risk groups represented the task force's professional experiential judgment regarding the relative likelihood of death occurring in association with these procedures. Since national mortality rate standards did not exist, the task force then set mortality rate ranges and mortality rate thresholds for each of the surgical risk groups. The mortality rate ranges was the task forces' estimate of the expected national mortality rate for each of the risk groups. ICD-9-CM procedures classified as low risk should have a national rate no greater than one percent while those classified as high risk could have rates between 10 and 20 percent. The mortality rate thresholds were defined by the task force as the rate "...which if exceeded would raise questions about the quality of care provided and would trigger a systemwide review of individual cases to determine whether age or other risk factors could explain the unexpected rate or whether...substandard care was being provided."

National Hospital Discharge Survey (NHDS)

We attempted to calculate average rates for the non-VA hospital sector for the purpose of comparing the surgical experiences of the two hospital sectors. This was accomplished by using the NHDS data base. This annual survey, conducted by the National Center for Health Statistics, includes patients discharged from a national sample of nonfederal short stay hospitals. The stratified design ensured appropriate representation of hospitals of all sizes and geographic locations and enabled the generation of estimates applicable to the national population. The data base contains records of 192,083 discharges from 407 hospitals.

The NHDS has some of the same shortcomings as the PTF including: (1) absence of cause(s) of death; (2) failure to identify those who expired after being discharged from the hospital; and (3) absence of data on patient health status at the time of admission and before the conduct of surgery.

While the NHDS provides an overall framework for drawing comparisons, there are several features of the design of this survey which make it different from the VA's PTF and limit its usefulness. The NHDS is not an administrative system as is the PTF which focuses on recording the process of hospital care. Instead, it uses an abstract of the patient's medical record, and presents a summary of the patient's condition. Thus, principal surgical procedures are identified for data entry not all those performed during a trip to the O.R.

The age-sex distributions of the non-VA hospital population underscore the uniqueness of the population served by the VA. Over half of those discharged from non-VA hospitals are women, and not unexpectedly, children and teenagers make significant demands for hospital care. Furthermore the two hospital systems have different roles and functions. This is reflected by the fact that accidents, trauma cases and burn victims comprise a significant segment of the non-VA workload, but this is not the case with the VA medical care system. We eliminated records that only had diagnostic or palliative surgical procedures, leaving only 23,356 records representing approximately five million discharges taking place in non-VA hospitals across the country. Even restricted in this way, the surgical populations show a great deal of disparity. About 19%, of the surgical workload in non-VA hospitals were younger than 35, while only seven percent of the VA surgical population was in this age group. About 38% of VA surgical patients were in the age group 55-64 compared to only 19% in non-VA hospitals. Surprisingly, the older age group, 65- 74, places a considerable load on non-VA hospitals but is proportionally less in the VA.

It is clear that substantial differences remain in the two surgical populations, even after removing the obvious population segments and surgical procedures. The age distributions are vastly divergent, and left to themselves, would cause any comparison of mortality rates from the PTF and NHDS data to be suspicious. Any observed difference might likely be the result of these age differences rather than true differences in the mortality rates. We attempted to remove as large a portion of the age effect as possible by reweighing the NHDS data. As a result, mortality rates for the non-VA hospital sector cannot be interpreted as estimates of the surgical mortality rates for the U.S. population. Instead they have a highly artificial interpretation. They are estimates of what the mortality rates would be in the U.S. population of males aged 18 and older, if the non-VA hospital sector had provided surgical services to a population whose ages were similar to that of the VA's population. While this method tends to reduce the differences in mortality that are attributed to age, it cannot completely remove the effects of age, especially when comparisons are made between even smaller subgroups of these populations. This means that when comparing mortality rates for a specific surgical procedure, the age of patients actually contributing to the comparison could still be highly divergent.

We reduced the NHDS sample even further in size once we restricted our attention only to the tracking surgical procedures that were identified by the task force. The identification of males, aged 18 and older, who had a surgical tracking procedure, yielded only 5,725 discharges among which there were only 108 inpatient deaths within 30 days of surgery. The small size of this sample proved to be the limiting factor in determining the surgical mortality rate experience of the non-VA hospital sector. When we examined the 21 surgical procedure groups, only two of them could meet a minimal standard for reliability, that is, a rate based upon more than 10 deaths. In fact five of these procedure groups had such small samples that no surgical deaths were recorded among the NHDS data set. Therefore, our presentation of mortality rate standards was restricted to the level of the four risk groups. Even among these broad risk groups the sample sizes are not overly generous.

It must be remembered that the minimal standard of reliability previously applied is weak: requiring that more than 10 observed deaths go into the calculation of the mortality rate standard. Any rate based on such a small amount of data would be subject to a high degree of uncertainty. Serious misunderstandings and misinterpretations might occur if NHDS sampled rates are compared directly to VA rates without any regard to the high degree of uncertainty resulting from the small sample. Therefore, we adopted the use of the 99% confidence interval as a way of expressing the NHDS rates and calling attention to the degree of uncertainty present in the estimates of national non-VA rates. We wanted to emphasize that conclusions that might be drawn on the basis that VA rates exceeded the non-VA point estimates could be spurious. Instead we want to identify those instances where we had convincing evidence that the VA rates departed from the national non-VA hospital experience.

In summary the PTF and the NHDS data files have similar short comings, that is,

(1) provide data on the cause of death;
(2) identify those patients who died after being discharged from the hospital within 30 days of surgery;
(3) provide data on the health status of the patient upon admission and just prior to the conduct of surgery.

In spite of these problems these data bases did contain some very basic data which permitted descriptions of VA and non-VA surgical populations, the calculation of mortality rates associated with the occurrence of surgical risk groups, procedures and procedure groupings.

USING INTEGRATED DATA IN DETERMINING WISCONSIN PUBLIC HEALTH PRIORITIES FOR THE ELDERLY

Patricia Nametz, Wisconsin Center for Health Statistics

Escalating health care costs, increasing knowledge of the preventable causes of many diseases, and longer life expectancies have made it ever more critical for states to examine the causes of morbidity in their populations. In Wisconsin, the state agency charged with apportioning health promotion monies (the Bureau of Community Health and Prevention) contracts with the state Center for Health Statistics to collect and analyze data on several morbidity indicators and report them by age group in the context of mortality data and preventive strategies.[1] Programs to promote health and prevent disease can then be planned with a clearer picture of competing needs.

The Center for Health Statistics has used vital records data and the results of several state surveys to examine the most common health problems at various periods in life. Data are incorporated from the following sources:

Wisconsin Vital Records. Figures cited in this report are annual averages based on the most recent five years of death certificate data (1982-1986) for deaths occurring in Wisconsin regardless of residency.

Wisconsin Hospital Discharge Survey. This survey collected information on all inpatient discharges (including approximately 32,000 of persons aged 65 and over) during March and September 1986 from 138 of Wisconsin's 140 acute-care, non-federal hospitals.

Wisconsin Ambulatory Medical Care Survey. This random sample of all licensed office- and clinic-based physicians was stratified according to physician speciality and location (HSA). Each sampled physician provided information on approximately 30 randomly selected patient visits. The sample included about 2,300 visits by persons aged 65 and over.

Wisconsin Health Status Survey. This survey conducted telephone interviews with 2,382 Wisconsin households, selected by a random digit dialing procedure, and collected health information about 6,646 household members. The survey included information about the activities of daily living needs of 703 adults aged 65 and over.

This paper reports the most frequent causes of death, hospital discharge diagnosis, ambulatory care diagnosis, and household-reported functional impairment. Where sample sizes permit, data are analyzed by age groups within the 65+ population. After citing data from the surveys, the report discusses briefly the importance of age-specific prevention and health promotion strategies.

Some Characteristics of the 65+ Population in Wisconsin

Although the 65+ population is growing faster in the U.S. than in Wisconsin, Wisconsin has a somewhat higher proportion of elderly (12.8 percent in Wisconsin vs. 11.3 percent in the U.S. are aged 65 or over). Also, Wisconsin's 65+ population is somewhat older than its U.S. counterpart, with higher proportions of age groups 75 years old and older.

By other measures, the Wisconsin 65+ population is similar to the U.S. 65+ group. The male-to-female ratio is virtually identical in Wisconsin and the U.S. (about 68:100), as are the percentages of males (15 percent) and females (40 percent) living alone.

Wisconsin has a somewhat higher proportion of its 65+ population in nursing homes (6.8 percent) than does the U.S. (4.9 percent).

Causes of Death

Heart disease, cancer, and stroke cause roughly three-quarters of deaths among the 65+ population. These causes constitute similar proportions of total deaths in three age subgroups: 65-74, 75-84, and 85+ (Table 1). Rates

Table 1. Mortality Rates for Leading Causes of Death, Age 65 and Over, Wisconsin (Rates per 100,000 population)

Leading Cause Of Death	65 and Over	65-74	75-84	85 and Over
Heart disease	2,336	1,070	2,789	7,619
Cancer	1,036	806	1,250	1,617
Stroke	496	170	620	1,839
Pneumonia/Influenza	192	46	206	907
Diabetes	93	56	118	212
Chronic obstructive pulmonary disease	173	119	234	276
Injuries	73	41	86	202
Liver disease	28	31	27	13
Other causes	676	302	817	2,216
Total	5,102	2,641	6,146	14,901

Source: Rates are annual averages based on five years of Wisconsin vital records, 1982-1986.

of death from heart disease and stroke are dramatically higher for the population aged 85+ than for those aged 65-74: mortality rates for heart disease are about seven times higher and those for stroke are about 11 times higher. In contrast, rates of death from cancer increase approximately two-fold. Influenza and pneumonia show the most dramatic increment with age; rates of death from these causes are 20 times greater for the 85+ population than for the population aged 65-74.

Rates of death from injuries, arguably among the most preventable causes of death and morbidity, are about five times higher for those aged 85+ than for those aged 65-74. Falls are the leading cause of fatal injury in those 65 and over, exceeding even motor vehicle deaths.

The mortality rate for all causes at ages 65-74 is only about one-sixth that in the population aged 85+. Males have higher death rates at every age, although the difference narrows at the oldest ages.

Hospitalizations (First-listed Discharge Diagnoses)

The Wisconsin Hospital Discharge Survey provides estimates of the most frequent discharge diagnoses among adults age 65 and over; estimates can also be made for the age subgroups 65-74, 75-84, and 85+ (Table 2).

While three-quarters of deaths in the 65+ population, and in each of the age subgroups, are attributed to heart disease, cancer, or stroke, these diseases account for a much smaller proportion (35 percent) of the first-listed hospital diagnoses. Injuries, especially fractures, constitute a much larger proportion of the leading diagnoses. Other prominent first-listed hospital diagnoses are pneumonia and influenza, and gallbladder disease and other digestive disorders.

Among the most frequent hospital discharge diagnoses, heart diseases lead all other conditions reported as first-listed discharge codes for patients age 65 and over, at a rate of 64 per 1,000. Heart failure, the most frequently-cited condition in this large group of diseases, is a chronic cardiac dysfunction that is usually the result of coronary artery disease and/or hypertension. Discharge rates for heart disease are only moderately higher for the 85+ population (90 per 1,000) than for the population aged 65-74 (51 per 1,000).

Cancer (all sites) constitutes another frequent category of discharges, with a rate of 25 per 1,000 persons age 65 and over. Discharge rates for cancer do not change markedly across age subgroups.

Cerebrovascular disease (stroke) discharges are three times more frequent for the 85+ population (37 per 1,000) than for the population aged 65-74 (12 per 1,000).

Injuries are a major category of hospital discharge diagnoses among the elderly. In Table 2, fractures have been cited separately from other injuries because of their sizable proportion and their implications for prevention. Fractures and other injuries together have a discharge rate of 26 per 1,000 population. While the rate of hospital discharges for non-fracture injuries among the 65+ population remains fairly steady across age subgroups, the rate for fractures increases dramatically--from 8 per 1,000 to 40 per 1,000. This is evidence of the increasingly severe consequences of falls at older ages.

First-Listed Ambulatory Care Diagnoses

The Wisconsin Ambulatory Medical Care Survey provides estimates of the most frequent diagnoses for visits to physicians' offices and outpatient facilities (Table 3). The size of the survey sample allows estimates for only two age subgroups within the 65-and-over population: ages 65-74 and ages 75+. Thus differences in visit rates that might exist at older ages will be obscured.

As with hospital discharges, ambulatory visits are not as dominated as are mortality figures by heart disease, cancer, and stroke diagnoses, although these or their precursors remain major categories.

High blood pressure is the leading ambulatory care diagnosis for older adults. This is the first-listed diagnosis in about 10 percent of visits to physicians, at a rate of about 541 visits per 1,000 population. Cancer is another leading diagnosis category, at 384 per 1,000, as is heart disease (304 per 1,000). Other frequent diagnoses include diabetes mellitus,

Table 2. Hospital Discharge Rates by Diagnostic Category, Age 65 and Over, Wisconsin, 1986 (Rates per 1,000 population)

First-Listed Diagnosis (ICD Codes)	65 and Over	65-74	75-84	85 and Over
Heart disease (410-429,440-448)	4	51	77	90
Cancer (140-209)	25	23	28	26
Stroke (430-438)	19	12	25	37
Fractures (800-829)	14	8	18	40
Pneumonia/Influenza (480-487)	13	7	16	30
Injuries other than fractures (830-999)	12	11	13	16
Digestive disorders (570-579)	12	10	14	18
All other	150	129	175	189
Total	310	252	365	445

Source: 1986 Wisconsin Hospital Discharge Survey

Table 3. Physician Visit Rates by Diagnostic Category, Age 65 and Over, Wisconsin, 1986 (Rates per 1,000 population)

Principal Diagnosis (ICD Codes)	65 and Over	65-74	75 and Over
High blood pressure (401)	541	495	608
Cancer (all sites) (140-208)	384	383	385
Heart disease (410-414,426-428)	304	224	420
Diabetes mellitus (250)	244	251	233
Symptoms, signs, and ill-defined conditions (780-789)	229	247	201
Injuries and poisoning (800-999)	227	190	282
Glaucoma (365)	166	149	192
Bone and joint disorders (715)	154	135	182
Cataracts (366)	151	120	196
All other diagnoses	2,905	2,946	3,247
Total	5,305	5,140	5,947

Source: Wisconsin Ambulatory Medical Care Survey, 1983-84

injuries, eye conditions such as glaucoma and cataracts, and joint disorders.

The overall visit rate increases only moderately between ages 65-74 and 75+, from 5,140 per 1,000 to 5,947 per 1,000, an increase of about 16 percent. Heart disease visits display the greatest increase, nearly doubling between the two groups. Visit rates for injuries increase by 50 percent. Visits for bone and joint disorders such as arthritis increase by 30 percent, and those for high blood pressure by 20 percent.

Household Survey Estimates of Functional Needs

The 1984 Wisconsin Health Status Survey included information about 703 adults ages 65 and over. Estimates reported here are based on information from each household's "most knowledgeable" adult. Since this was a household survey, it did not include persons in nursing homes or other institutional settings. It also did not reach persons without telephones, who might be presumed to be poorer (and perhaps older) than the rest of the 65+ population.

Among the data collected was information about needs for help with activities of daily living (ADL), including walking, climbing stairs, going outside, getting out of bed, getting dressed, eating, bathing, continence, and using the toilet. Also collected were reported needs for help with "instrumental" activities of daily living (IADL), such as meal preparation, money handling, shopping, and chores; and medical needs, including taking medications, administering injections, and changing bandages. The sample size allows examination of the differences in reported needs between two age subgroups (Table 4).

Of the surveyed adults age 65 and over, seven percent needed assistance with one or more of the activities of daily living (ADL). Of those 65-74 years of age, 4 percent needed help with ADL needs. Of those 75 and over, 14 percent needed such help. The older age group thus had reported ADL needs 3.5-fold more frequently than did the younger group, even at the comparatively young age break of 75+.

IADL needs also increased with increasing age; 5 percent of those aged 65-74 reported such needs vs. 21 percent of those aged 75+. Reported medical needs varied from about 2 percent of those 65-74 to about 6 percent of those 75 and over.

Across all three categories of functional needs, about 16 percent of Wisconsin adults age 65 and over were reported to need help in at least one of the categories. A sharp increase in needs is seen with age; 9 percent of those 65-74 vs. 31 percent of those 75 and over were reported to need assistance with one or more of the ADL, IADL, or medical needs.

Policy Considerations

The goal of health promotion for today's elderly adults is not so much to achieve increases in longevity as to allow each person

Table 4. Reported Functional Needs among Wisconsin Adults Age 65 and Over, 1984

Reported Functional Need	Percentage		
	All 65+	65-74	75+
Medical needs	3%	2%	6%
Activities of daily living (ADL)	7%	4%	14%
Instrumental activities of daily living (IADL)	10%	5%	21%
Any reported need	16%	9%	31%

Source: 1984 Wisconsin Health Status Survey an independent and rewarding life in older age, unlimited by health problems that can be prevented or ameliorated. Health promotion programs must include strategies for primary prevention of chronic disabling conditions as well as for detecting and managing disabilities. Such initiatives must give particular attention to the major health and disability problems of this age group, including cardiovascular diseases, cancer, injuries, influenza and pneumonia, diabetes, osteoporosis, arthritis and other joint disorders, and sensory loss. Prevention efforts therefore should focus on health promotion, risk reduction, and detection of early signs of disease as well as on general health maintenance.[2]

While a general overview of survey data such as that presented here is perhaps most useful as a means of providing a context for health promotion and prevention efforts, it is also possible to look more closely at particular causes of morbidity with a view towards prevention.

The problem of falls provides one example. Both the hospital and the ambulatory surveys suggest the importance of injuries as a source of morbidity and disability for older adults, especially at older ages. Fall prevention strategies would be a useful component of client education programs sponsored by agencies serving the 65+ population. Physicians and other health professionals who provide care to older adults also can play a part in fall prevention. Although age-related changes such as decreased vision and unstable gait often contribute to falls, gerontologists have noted that a fall can also be the sign of a medical problem that needs to be investigated. Many medical conditions can predispose to falls, as can various classes of drugs.[3 4] Improved understanding of the causes and prevention of osteoporosis will help to decrease the severity of the consequences of falls. Also, exercise programs to increase joint flexibility and muscular strength can improve an older person's ability to maintain balance and avoid falls. Designing or improving housing to provide a safer environment is another important factor in reducing the incidence and severity of fall-related injury.

Taken together, data from these surveys provide broad estimates of the major health problems in Wisconsin's 65+ population, and some idea of the relative health of the early decades as opposed to the later decades of this increasingly large and diverse group. The Wisconsin Center for Health Statistics uses these and other data to produce a series of reports for health planners, legislators, and other public policymakers in Wisconsin.

These reports provide estimates of the mortality and morbidity associated with major causes of disease and injury, and describe the roles that individuals, public health agencies, and health care professionals can play in lessening these burdens. Changes in personal behavior, professional awareness, and programmatic emphasis will be of increasing importance as the population ages, and greater numbers are at risk of chronic illness and disability.

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WHERE DO OLDER PEOPLE DIE?

Anthony Lenzer, University of Hawaii at Manoa

Introduction

Place of death is an important variable in thanatological research. Where one dies -- whether at home, in an institution or elsewhere -- affects the type of terminal care which can be given; the cost of such care; the amount of control the patient and family have over the dying process; patient, family and staff interaction; and the types of stresses affecting all participants in the terminal process. And while death is a universal event, terminal illness is of special concern to gerontologists. A major demographic trend of this century has been the shifting of the time of death from infancy, childhood and young adulthood to the middle and later years (1). Although death rates among the elderly have declined, the enormous increase in the older population has meant increased numbers of elderly deaths.

Place of death. This century has also seen a shift in place of death from the home to the hospital or other institution. In 1949, for example, approximately half of U.S. deaths occurred at home and half in institutions. Only nine years later (1958), 61% of U.S. deaths occurred in institutions (2). More recent data, from state and community studies, indicates that the trend toward the "institutionalization" of death continues (3)(4). This trend has been associated with advances in medical technology and the professionalization of institutional care. Today, 70-80% of the chronically ill die in hospitals or nursing homes.

The nature of terminal illness is now quite different from what it was in the past. In the U.S. in 1900, the three leading causes of death were influenza and pneumonia; tuberculosis; and gastritis and enteritis (5). These were acute conditions, for which the physician could do relatively little, other than provide comfort and care in the patient's own home. Today the leading causes of death are diseases of the heart; cancer; and stroke. Two-thirds of all deaths are attributed to these causes (6). Elaborate technologies have been developed to deal with each. Hospital care is usually required during some stage of each illness.

Appropriateness of the place of care. As indicated above, most terminal care is provided in acute care hospitals, and some in other institutions. The basic mission of the hospital is diagnosis, treatment, and cure of illness. Once a condition is no longer treatable, it is debatable whether the hospital is an appropriate place of death. One recent article suggests that the dying patient has five basic needs: independence; dignity; acceptance by others of his individual approach to dying; relief of symptoms; and physical care. It suggests that these needs can better be met at home, if the family is able to manage the burdens of care (7). Another author stresses the need for families and patients to spend time together saying goodbye. He feels that this is best done at home (8). P.W. Were feels that hospitalized terminally ill patients often suffer unnecessary pain due to the attitudes of hospital staff, as well as the reluctance of some relatives to allow such patients to die at home (9).

Cost. The cost of terminal illness represents an increasing burden on society, as well as on the patient and family. In 1982, for example, about 20% of Medicare's $49 billion in expenditures went for patients in their last six months of life. A large proportion of this sum was spent for care during the last 30 days of life. Furthermore, a recent American Hospital Association survey of the general public showed that 70% favored terminating life support systems for patients with little or no hope of survival in order to reduce hospital and insurance rate increases (10). Does place of death make a difference in cost of terminal care? The National Hospice Survey analyzed data on 4,000 patients in twenty five hospice programs and twelve conventional care sites during the period 1981-83. Preliminary results indicated that hospital-based hospice care costs were significantly higher than those of home-care type hospice programs. Home care hospice programs were also less costly than conventional home and institutional care. However, cost issues are so complex that even this major study should be seen only as suggestive, not definitive (11).

The following figures illustrate current differences in daily charges for various types of care for terminal patients in Honolulu at the time of writing. These figures are approximate, and are not representative of all Honolulu care providers: Hospice Home care - $70; Intermediate Care Facility care - $110; Skilled Nursing Facility care - $141; Acute Hospital care - $257; and Intensive Care Unit care - $885/day (12).

Purpose and Methodology of this Paper

This paper examines one major mortality variable, i.e., where people die, in one state, Hawaii, over a period of nineteen years (1968-86). It focuses on one age group, i.e., persons aged 65 and older. However, some comparisons are made between the elderly and other age groups. It is based on Hawaii death certificate data for the period (all available computerized records) Only Hawaii resident deaths were used in this analysis. Basic data tables were prepared by the Hawaii Department of Health.

Place of Death. Place categories used herein include (a) home; (b) acute care hospital; (c) long term care facility (LTCF); and (d) elsewhere. Such classification required considerable reorganization of health department coding systems. For example, the LTCF category, for the purpose of this paper, included SNFs; ICFs; and specialty hospitals (i.e., mental, chronic disease, mental retardation/developmental disability, and rehabilitation facilities). Care and boarding homes were not included, as they could not be accurately identified from the death certificate data. The residual category, elsewhere, includes deaths occurring in clinics; doctors offices; on the streets and highways; in the ocean, etc. "Home" deaths, therefore, are those which occurred in none of the other places. Deaths at home had to be derived in this roundabout fashion, as the death certificate does not specify whether the address at which the individual dies is in fact his or her home.

Research Questions: (a) are there any trends which distinguish the elderly from other age groups with regard to place of death? (b) within the elderly population, are there differences based on age, sex, marital status, ethnicity, or cause of death? (c) can any relationship be found between the number of acute hospital and long-term care facility beds and where older people die? (d) can any relationship be seen between the advent of the DRG system in Hawaii and where older people die?

The findings reported below summarize broad trends revealed by frequency distributions of the data. Statistical analysis of the results has yet to be done. Hence these should be seen as preliminary findings.

Findings

(a) Increasing Number of Deaths, Total and Elderly. The total number of resident deaths in the state grew from 4,024 in 1968 to 5,786 in 1986 (a 44% increase). Deaths among persons aged 65 and older went from 2,059 to 3,801 during the period (an 85% increase). Deaths among the very old (aged 85 and older) were 405 in 1968 compared with 1,056 in 1986 (an increase of 161%).

(b) Deaths by Age. The general, and very clear, trend has been to push death back into the later years. For example, in 1968, 51% of all deaths occurred at 65 or older, compared with 65% of all deaths in 1986. By contrast, deaths among persons under 25 years of age decreased from 12% of the total in 1968 to 6% in 1986.

(c) Place of Death. From 1968-86, the general pattern of place of death for the population as a whole remained relatively constant: 58-69% died in hospitals; 17-22% died at home; 9-12% died in LTCFs, and 1-5% died in other locations.

(d) Broad Age Group Differences. Four broad age groups (under 25 years, 25-44 years, 45-64 years, and 65 years and older) were used in this analysis. Hospital deaths. Over half of each age group dies each year in hospitals. Members of the youngest group (under 25 years) are most likely of all to die in hospitals. Deaths at Home. Young adults (25-44 years) are the most likely to die at home, and the elderly are least likely to do so. Between 30-44% of young adults died at home during the period studied, compared with 13-20% of the elderly. LTCF deaths. As might be expected, the great majority of LTCF deaths occur among people over 65. No more than 6% of the three younger groups died in LTCFs in any given year, whereas 12-19% of elderly deaths occurred in such facilities.

Place of death for the elderly is shown in Figure 1. This shows that most older people died in hospitals during the period, with some fluctuations in the pattern of hospital deaths. The percent dying at home increased somewhat between 1968-86, while the percent of LTCF deaths decreased.

(e) Age Differences Within the Elderly Population. Three categories were compared: 65-74 years, 75-84 years; and 85 years and older. Hospital Deaths. "Younger" older people were more likely to die in hospitals than "older" older people. For example, in 1986, the percent of each age group dying in hospitals was as follows: 65-74 years (71%), 75-84 years (64%), and 85 years and older (52%). Deaths at home. In 14 of the 19 years examined, there was a clear relationship between age and dying at home: the younger you were, the more likely you were to do so. In 1986, for example, the percent of each age group dying at home was as follows: 65-74 years (23%), 75-84 years (21%), and 85 years and older (17%). LTCF deaths. Within the elderly population, LTCF deaths increased with age. In 1986, for example, 4% of the 65-74 deaths; 13% of the 75-84 deaths; and 24% of the 85 and older deaths took place in LTCFs.

(f) Sex Differences. The clearest difference is with regard to LTCF deaths: in every year, older women are more likely to die in such facilities than are older men. For both sexes, however, the percent dying in LTCFs has declined since 1968. A second difference is that older men are more likely than women to die in hospitals. There is, however, no clear difference in the proportion of older men and women who die at home. The percent of both sexes dying at home has been increasing since 1968. This unexpected finding is shown in Figure 2.

(g) Marital Status Differences. The three marital status categories used were married; widowed; and other (single, separated, and divorced). Hospital deaths. A higher proportion of married persons died in hospitals than either of the other categories. Widowed persons are the least likely to die in such institutions. Home deaths. Contrary to expectations married persons are not consistently more likely to die at home than are the non-married! Widowed persons are the most likely to die in LTCFs, and married persons the least likely to do so. (Widowhood is associated with more advanced age, which also predicts LTCF death.)

(h) Ethnic Differences. Hawaii has no ethnic or racial "majority." The main ethnic minorities are: Hawaiians, Chinese, Filipinos, Japanese, and Caucasians. Of these five groups, Filipinos had the highest percentage of deaths in hospitals, and Caucasians the lowest. On the other hand, Hawaiians had the highest percentage of home deaths (in 11 of the 19 years examined). Japanese and Filipino elderly were the least likely to die at home. During this period, Japanese, Caucasian, and Chinese elderly more frequently died in LTCFs than did Filipinos or Hawaiians.

(i) Cause of Death. This analysis identified three broad types of causes of death: cancer; all diseases other than cancer; all other causes (principally accidental injuries, suicide, and homicide). Cancer deaths. Between 1968 and 1986, there was a substantial increase in the proportion of cancer deaths taking place at home, and a decrease in the proportion taking place in LTCFs (in 1986, a quarter of elderly cancer patients died at home). The pattern for patients with diseases other than cancer was similar, except that fewer died at home and more in LTCFs. For the elderly, home injuries constitute the main component of the non-disease (all other causes) category. Thus it is not surprising to find a high proportion of deaths taking place at home, and an even higher proportion in hospitals.

(j) Changes in Number of Acute Hospital and LTCF Beds. Hawaii data on facility beds is currently available only for the period 1975-85. The state's 2,277 acute hospital beds in 1975 had increased to 2,449 (an 8% gain) by 1985. There were 3,346 LTCF beds in 1975. This included 2,812 nursing home (ICF/SNF) beds and 534 "specialty hospital" (TB, Psychiatric, Chronic disease, MR, and Rehabilitation) beds. In 1986, there were 2,701 nursing home and 879 specialty hospital beds (total: 3,580), an increase of 7%. The numbers of nursing home beds had actually declined, during a period when the elderly population greatly increased.

Between 1975-85, the percent of older people who died in hospitals increased slightly, and then returned to the 1975 level. During the same period, the percent who died in LTCFs declined from 19% to 14%.

Social and Health Policy Implications

(a) The majority of elderly patients continue to die in acute care hospitals. Yet the focus of hospital care -- and its image in the public mind -- is curing disease and life-saving technology. Hospitals, health personnel, and the public must recognize that terminal care remains the institution's second major function. Hospitals must develop appropriate terminal care programs, independently or in conjunction with hospices. This is especially important at a time when so many hospital patients are elderly, and deaths occur so frequently.

(b) The increasing proportion of elderly deaths which take place at home is encouraging, in light of the expressed desire of many older people to end their lives in familiar surroundings. This increase is perhaps related to greater availability of home care services; some liberalization of Medicare home health benefits; and Hospice coverage under Medicare. It may also reflect more knowledge about care on the part of caretakers in the home. On the other hand, increases in elderly home deaths since 1984 may also reflect pressures for hospital discharge generated by the DRG system. This appears to be a factor in Hawaii, where home deaths among the elderly increased from 17% in 1983 to 21% in 1984, the year that the DRG system was introduced in the state. However, more information is needed to understand the significance of the trend to at-home deaths.

(c) Although hard data is not currently available, it appears that a very small proportion of Hawaii's elderly are served by hospice programs. The Medicare hospice benefit should be examined to see what changes might be instituted to increase utilization of hospice services. Marketing of hospice programs, physician referral practices, and other local factors also need to be examined in this connection.

(d) LTCFs have traditionally been seen as places to die for older people. Yet a smaller proportion of the elderly now die in such institutions, and those who do are primarily the very old. As the hospital must recognize its terminal care obligations, so too must the LTCF recognize that an active and positive LTC program is at least as important as its terminal care responsibilities. And whether hospice programs can meet the needs of the very old people who now die in LTCFs remains to be seen.

(e) From the policy standpoint, perhaps the most intriguing finding of this study is the gradually increasing percentage of older people who die at home. This finding runs counter to expectations for two main reasons: first, because the elderly population is getting larger, getting older, and losing spouses and other support from its own generation; and, second, because growing numbers of potential caretakers -- i.e., middle-aged women -- are entering or re-entering the labor force. And so the question is: what social policies will insure that terminal care at home remains a humane and economically viable option for older people?

Footnotes

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Figure 1
Place of Death
Persons Aged 65 years and Older
Hawaii, 1968-1986

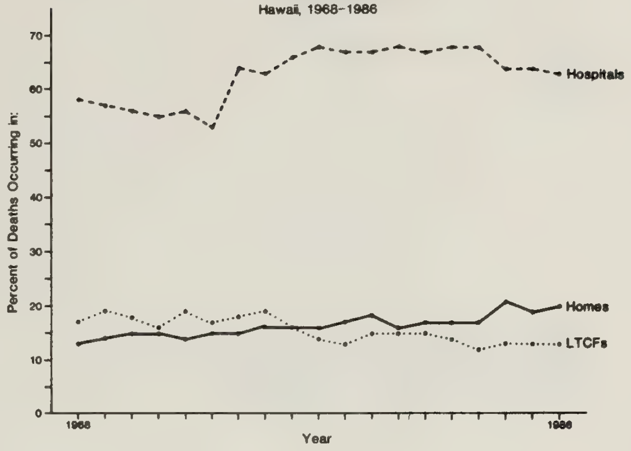
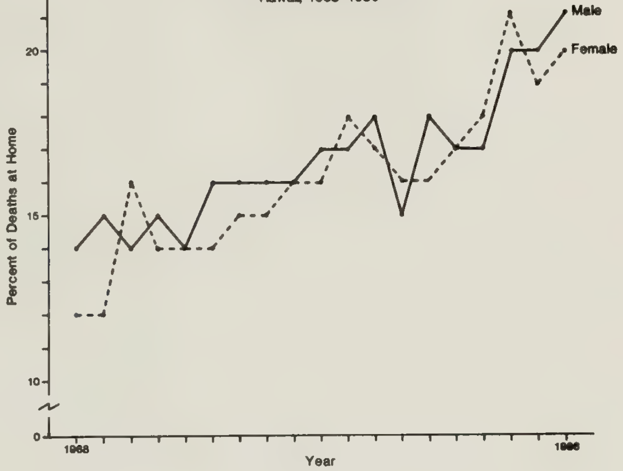


Figure 2
Deaths at Home by Sex
Persons Aged 65 years and Older
Hawaii, 1968-1986



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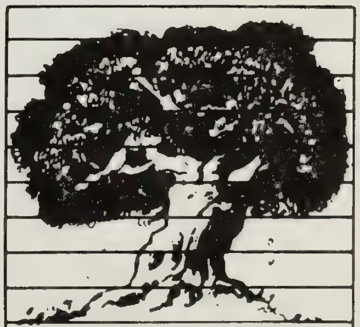
Session AA

Revisions to Standard Death Certificate



DATA FOR AN AGING POPULATION

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REVISIONS TO STANDARD DEATH CERTIFICATES - INTRODUCTION

Frederick L. King, Minnesota Department of Health

The vital statistics of the United States are collected and published through a decentralized, cooperative system. Responsibility for registration of vital events is vested in the individual States and certain independent registration areas.

The degree of uniformity necessary for national statistics has been achieved by periodic issuance of recommended standards from the responsible national agency and the cooperative adoption of these standards by the individual registration areas. The first standard death certificate was developed in 1900. The revision which we will be discussing this afternoon will be introduced by most states in Janaury, 1989 and is the ninth revision of the death certificate.

Since the production of national vital statistics is dependent upon cooperation between the National Center for Health Statistics and the individual registration areas, the development of the standard certificates must be a cooperative effort. In the revision process, opinions were solicited from persons involved in preparation, registration, and tabulation of the records and from consumers of the data to determine whether changes needed to be made and, if so, where.

In addition to State Registrars and statisticians, the subgroup to evaluate the death certificate consisted of a representative of the National Funeral Directors Association, a pathologist, medical examiner, a representative of the American Medical Association, and a researcher-epidemiologist.

We are fortunate this afternoon to have as our speakers three individuals who served on the standard certificate committee. Dr. Patricia Potrzebowski chaired the death subgroup, Dr. J. David Curb served on the death subgroup, and Dr. Leo Estrada served on the birth subgroup but also provided valuable assistance to the other certificate subgroups as they considered the ancestry item.

MAJOR CHANGES IN THE 1989 REVISION OF THE U.S. STANDARD CERTIFICATE OF DEATH

Patricia W. Potrzebowski, Pennsylvania Department of Health

In his introduction, Mr. King covered the process and committee structure of the standard certificate revision. I will discuss what changes were made to the death certificate and why. The next two speakers will discuss some of the implications of those changes.

In order to meet health data needs of the 1990's, (balancing statistical considerations with legal requirements), the Panel to Evaluate the U.S. Standard Certificates and Reports adopted two criteria:

(1) An item must be needed for personal identification or for establishment of the time and place of the event; or an item must have a high priority among data needed for scientific or public health purposes.

(2) An item must be obtainable; that is, it must be possible to acquire complete and accurate information about the items without imposing an undue burden upon the data provider.

The U.S. Standard Certificate of Death has remained essentially the same for many years. Most of the items on the current certificate have been included since 1939 or 1949. Prior to the 1989 revision, the items required for the certification of cause of death had not changed since 1949. (Figure 1, which shows the 1989 U.S. Standard Certificate of Death, follows the text.)

The subcommittee's overriding concern in the current revision process was improvement of the quality of data on mortality. The accuracy of data reported in the medical certification section of the certificate has long been a concern. In a comparison of death certificates to hospital records, Leadbeatter(1) concludes that:

> "...an unacceptably large number of medical certificates of cause of death are imprecise or inaccurately completed...because of ignorance of, or failure to apply, the principles of death certification and not because relevant information is lacking".

As a result of these concerns a number of seemingly minor, but complementary changes have been made to the death certificate which, we hope, will have an additive effect in improving the quality of the data collected.

The first such change is the inclusion of instructions for completing the certificate, both on the face of the certificate and also, in more detail, on the back. (See Figure 2, following text.) We realize that persons who complete death certificates frequently will probably not read these instructions, but we hope they will be helpful to those who are not familiar with the form.

There are also handbooks published by the National Center for Health Statistics (NCHS) with more detailed directions for funeral directors, medical examiners/coroners, hospital staff, and physicians, but we recognize that many of these people may not have a handbook readily available. The most important items and the most confusing items (cause of death and medical certificate, residence of decedent, and place of death) were chosen to be included in the instructions on the reverse side of the form. Of particular interest are the two examples of cause of death, which show these sections properly completed for two cases, one a fatal injury, and the other a decedent with a number of chronic diseases.

The second change is the provision of additional space in Parts I and II of the medical certification section. This change recognizes the importance of multiple cause of death data, particularly in the aging population, where a number of chronic conditions may coexist and contribute to death. In 1980, according to NCHS data, about 25% of all deaths were attributable to four or more causes.

If properly completed, Part I of the cause of death section should list only one cause per line. By allowing more space in both Parts I and II, we hope that we will encourage physicians to report more completely all the diseases, injuries, and complications that caused death, and all other significant conditions which may have contributed to death.

This will be reinforced by a Panel recommendation urging the Department of Health and Human Services to work with organizations such as the American Medical Association to develop and implement programs to improve physician reporting of the causes of death. The recommendation results from a recognition of the need for increased physician training in the medical certification of death. It is also an attempt to respond to the concerns described by Leadbeatter(1), mentioned previously.

Two other factors may affect the accuracy and completeness of the medical certification. First, the certifier's knowledge of the decedent's medical history and final illness may be limited because the certifier has never attended the decedent or has attended him or her for a limited time. Markush et al.(2) concluded that there is a suggestion that short attendance is related to generally less well substantiated diagnosis. It is probably reasonable to assume that this conclusion can be extended to instances in which the certifier has never attended the deceased; for example, when the medical certification is prepared by a physician other than the attending physician in the attending physician's absence. A second and related factor is the pressure on physicians to complete the medical certification promptly so that funeral arrangements can proceed.

Because the physician best qualified to complete the medical certification may not be available at the time of death, the new certificate includes an optional provision for two physician signatures. If the attending physician is not present, another physician can pronounce and certify the time and place of death. The body can then be released to the funeral director who will obtain the certification of the cause of death from the attending physician at a later time.

This system is currently in use in two states. It is similar to a recommendation of the College of American Pathologists' National Autopsy Data Bank Committee. That group recommends a two part death certificate with one part to meet the immediate legal requirements and a second containing the medical certification and other statistical data which may be completed at a later date. It is anticipated that the revision proposed by the Panel will expedite the release of bodies to funeral directors and, at the same time, improve the quality and completeness of the causes of death listed on the certificate.

The Panel made a second major recommendation regarding death certification which does not appear on the certificate. This recommendation involves the order in which the causes of death are listed in Part I of the medical certification section. Currently, the immediate cause is listed on the first line, followed by antecedent causes in order on the following lines, with the underlying cause listed last. The Panel considered reversing the order and listing the underlying cause on the first (top) line with the resulting conditions listed sequentially on the following lines. (The proposed change is shown in Figure 3, following the text.) The rationale for this proposal was that since this is the logical sequence used by physicians in medical diagnosis and in most medical records, it would result in fewer sequencing errors and improved data quality.

However, the Panel recognized that this would be a major change to a critical data item. Therefore it was recommended that NCHS undertake a study to determine whether reversing the sequential order would improve the reporting of causes of death. The recommendation also urges NCHS to complete the study in time to implement the revised format, if warranted, simultaneously with the implementation of the tenth revision of the International Classification of Diseases (ICD-10) for coding cause of death. Implementation of ICD-10 is scheduled for 1993.

I understand that there are now some problems with respect to this recommendation. NCHS apparently does not have adequate funds to conduct the study, so it appears at this time that this recommendation will not be implemented. This is unfortunate because this relatively inexpensive study could demonstate the need for a change which might then improve data quality substantially.

Two statistical items were added to the death certificate. One is an item to identify decedents of Hispanic origin. An alternative general ancestry item is also available for use by states with small Hispanic populations or with other significant ethnic groups. Either of these items will permit an examination of mortality patterns in the Hispanic community. Lack of national data about the Hispanic population has received considerable attention. Since the early 1980s, about half of the states, including almost all of those with significant Hispanic populations, have collected Hispanic origin or other ethnicity data on their certificates. The inclusion of Hispanic and ancestry items on the 1989 Standard Certificates reflect the experience of these states.

The second new statistical item is the decedent's education, which was intended as a proxy measure for socioeconomic status. This item is easily collected, easier to code, and, it is hoped, will provide more accurate information than does the stated occupation of the decedent.

Minor modifications to the U.S. Standard Certificate of Death include the use of checkboxes to obtain information about the place of death, the method of disposition, and the manner of death. An item was also added to determine whether autopsy findings were available to the certifier prior to completion of the medical certification. The state license numbers of the physician who pronounced death, the certifying physician (if different), and the funeral service licensee were also added. In addition, the decedent's city of birth was added to assist registrars in matching birth and death certificates.

The 1989 standard death certificate is now 8½ X 11 inches in size, which is an increase over the previous 7½ X 8½ inch document. This has presented minor problems for some vital records offices.

The U.S. Standard Certificates are models for the states, designed to ensure uniform national vital statistics data. Although state adoption of these documents is voluntary, past experience has been good, especially for statistical items included in the NCHS minimum data set. Of the 21 items currently used by NCHS for national tabulations, 19 are on certificates used to report over 99 percent of all deaths and one is on certificates used to report 90 percent of deaths. Only one item, "Was decedent dead on arrival at the hospital?", is not now uniformly reported. This item is present on certificates for reporting 77 percent of U.S. deaths.

However, it appears that there are some problems with acceptance by states of two of the recommendations for the 1989 death certificate. These items are the additional lines for cause of death, and the option for two different physicians to pronounce death and to certify cause of death. If you agree with the Panel that these two items are worthwhile, you may wish to encourage your state health agency to conform to the U.S. standard.

In summary, while the changes to the death certificate are not perhaps as extensive as changes to other certificates, they are the most substantial changes that have been made to the death certificate in the past 30 or 40 years. While many of these changes appear to be minor when looked at individually, it is hoped that they will have cumulative impact on improving the quality of data collected on death certificates.

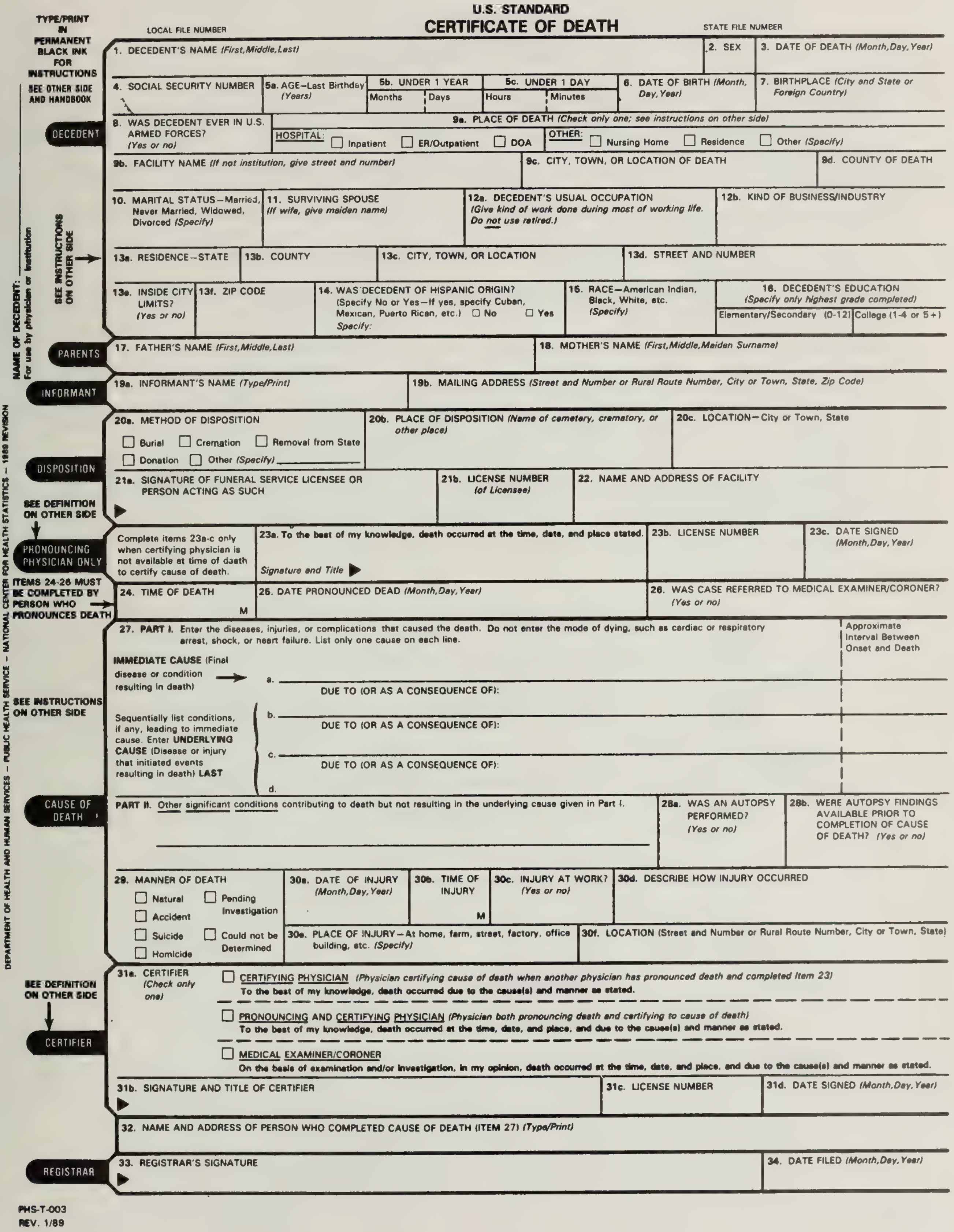
I want to acknowledge the contributions of the entire death certificate subcommittee including Fred King, Minnesota; Omar Greeman, Kentucky; Howard Raether, representing the National Funeral Director Association; Toby Kircher, representing the College of American Pathology; George Gantner, representing the National Medical Association; and David Curb, a researcher/epidemiologist. Excellent staff support was also provided by Harry Rosenberg, Eve Powell-Griner, Marilyn McMillan, Mary Lou Dundon, George Gay and others at NCHS.

References

(1) Leadbeatter, S.: Semantics of Death Certification. J Royal College Phys. Lond. 1986; 20:129-132

(2) Markush, R.E., Schaaf, W.E., Seigel, D.G.: The Influence of the Death Certifier on the Results of Epidemiologic Studies. J Natl. Med. Assoc. 1967; 59: 105-113.

Figure 1



U.S. STANDARD
CERTIFICATE OF DEATH

TYPE/PRINT IN PERMANENT BLACK INK FOR INSTRUCTIONS SEE OTHER SIDE AND HANDBOOK

LOCAL FILE NUMBER

STATE FILE NUMBER

DECEDENT

1. DECEDENT'S NAME *(First, Middle, Last)*
2. SEX
3. DATE OF DEATH *(Month, Day, Year)*
4. SOCIAL SECURITY NUMBER
5a. AGE–Last Birthday *(Years)*
5b. UNDER 1 YEAR: Months | Days
5c. UNDER 1 DAY: Hours | Minutes
6. DATE OF BIRTH *(Month, Day, Year)*
7. BIRTHPLACE *(City and State or Foreign Country)*
8. WAS DECEDENT EVER IN U.S. ARMED FORCES? *(Yes or no)*
9a. PLACE OF DEATH *(Check only one; see instructions on other side)*
HOSPITAL: ☐ Inpatient ☐ ER/Outpatient ☐ DOA   OTHER: ☐ Nursing Home ☐ Residence ☐ Other *(Specify)*
9b. FACILITY NAME *(If not institution, give street and number)*
9c. CITY, TOWN, OR LOCATION OF DEATH
9d. COUNTY OF DEATH
10. MARITAL STATUS–Married, Never Married, Widowed, Divorced *(Specify)*
11. SURVIVING SPOUSE *(If wife, give maiden name)*
12a. DECEDENT'S USUAL OCCUPATION *(Give kind of work done during most of working life. Do not use retired.)*
12b. KIND OF BUSINESS/INDUSTRY

SEE INSTRUCTIONS ON OTHER SIDE

13a. RESIDENCE–STATE
13b. COUNTY
13c. CITY, TOWN, OR LOCATION
13d. STREET AND NUMBER
13e. INSIDE CITY LIMITS? *(Yes or no)*
13f. ZIP CODE
14. WAS DECEDENT OF HISPANIC ORIGIN? (Specify No or Yes–If yes, specify Cuban, Mexican, Puerto Rican, etc.) ☐ No ☐ Yes Specify:
15. RACE–American Indian, Black, White, etc. *(Specify)*
16. DECEDENT'S EDUCATION *(Specify only highest grade completed)* Elementary/Secondary (0-12) | College (1-4 or 5+)

NAME OF DECEDENT: For use by physician or institution

PARENTS

17. FATHER'S NAME *(First, Middle, Last)*
18. MOTHER'S NAME *(First, Middle, Maiden Surname)*

INFORMANT

19a. INFORMANT'S NAME *(Type/Print)*
19b. MAILING ADDRESS *(Street and Number or Rural Route Number, City or Town, State, Zip Code)*

DISPOSITION

20a. METHOD OF DISPOSITION
☐ Burial ☐ Cremation ☐ Removal from State
☐ Donation ☐ Other *(Specify)* ________
20b. PLACE OF DISPOSITION *(Name of cemetery, crematory, or other place)*
20c. LOCATION–City or Town, State
21a. SIGNATURE OF FUNERAL SERVICE LICENSEE OR PERSON ACTING AS SUCH ▶
21b. LICENSE NUMBER *(of Licensee)*
22. NAME AND ADDRESS OF FACILITY

SEE DEFINITION ON OTHER SIDE

PRONOUNCING PHYSICIAN ONLY

Complete items 23a-c only when certifying physician is not available at time of death to certify cause of death.
23a. To the best of my knowledge, death occurred at the time, date, and place stated. Signature and Title ▶
23b. LICENSE NUMBER
23c. DATE SIGNED *(Month, Day, Year)*

ITEMS 24-26 MUST BE COMPLETED BY PERSON WHO PRONOUNCES DEATH

24. TIME OF DEATH M
25. DATE PRONOUNCED DEAD *(Month, Day, Year)*
26. WAS CASE REFERRED TO MEDICAL EXAMINER/CORONER? *(Yes or no)*

SEE INSTRUCTIONS ON OTHER SIDE

CAUSE OF DEATH

27. PART I. Enter the diseases, injuries, or complications that caused the death. Do not enter the mode of dying, such as cardiac or respiratory arrest, shock, or heart failure. List only one cause on each line.

Approximate Interval Between Onset and Death

IMMEDIATE CAUSE (Final disease or condition resulting in death) → a. ____________
DUE TO (OR AS A CONSEQUENCE OF):
b. ____________
DUE TO (OR AS A CONSEQUENCE OF):
c. ____________
DUE TO (OR AS A CONSEQUENCE OF):
d. ____________

Sequentially list conditions, if any, leading to immediate cause. Enter UNDERLYING CAUSE (Disease or injury that initiated events resulting in death) LAST

PART II. Other significant conditions contributing to death but not resulting in the underlying cause given in Part I.
28a. WAS AN AUTOPSY PERFORMED? *(Yes or no)*
28b. WERE AUTOPSY FINDINGS AVAILABLE PRIOR TO COMPLETION OF CAUSE OF DEATH? *(Yes or no)*
29. MANNER OF DEATH
☐ Natural ☐ Pending Investigation
☐ Accident
☐ Suicide ☐ Could not be Determined
☐ Homicide
30a. DATE OF INJURY *(Month, Day, Year)*
30b. TIME OF INJURY M
30c. INJURY AT WORK? *(Yes or no)*
30d. DESCRIBE HOW INJURY OCCURRED
30e. PLACE OF INJURY–At home, farm, street, factory, office building, etc. *(Specify)*
30f. LOCATION (Street and Number or Rural Route Number, City or Town, State)

SEE DEFINITION ON OTHER SIDE

CERTIFIER

31a. CERTIFIER *(Check only one)*
☐ CERTIFYING PHYSICIAN *(Physician certifying cause of death when another physician has pronounced death and completed Item 23)*
To the best of my knowledge, death occurred due to the cause(s) and manner as stated.
☐ PRONOUNCING AND CERTIFYING PHYSICIAN *(Physician both pronouncing death and certifying to cause of death)*
To the best of my knowledge, death occurred at the time, date, and place, and due to the cause(s) and manner as stated.
☐ MEDICAL EXAMINER/CORONER
On the basis of examination and/or investigation, in my opinion, death occurred at the time, date, and place, and due to the cause(s) and manner as stated.
31b. SIGNATURE AND TITLE OF CERTIFIER ▶
31c. LICENSE NUMBER
31d. DATE SIGNED *(Month, Day, Year)*
32. NAME AND ADDRESS OF PERSON WHO COMPLETED CAUSE OF DEATH (ITEM 27) *(Type/Print)*

REGISTRAR

33. REGISTRAR'S SIGNATURE ▶
34. DATE FILED *(Month, Day, Year)*

DEPARTMENT OF HEALTH AND HUMAN SERVICES – PUBLIC HEALTH SERVICE – NATIONAL CENTER FOR HEALTH STATISTICS – 1989 REVISION

PHS-T-003
REV. 1/89

Figure 2

INSTRUCTIONS FOR SELECTED ITEMS

Item 9. — Place of Death
If the death was pronounced in a hospital, check the box indicating the decedent's status at the institution (inpatient, emergency room/outpatient, or dead on arrival (DOA)) If death was pronounced elsewhere, check the box indicating whether pronouncement occurred at a nursing home, residence, or other location. If other is checked, specify where death was legally pronounced, such as a physician's office, the place where the accident occurred, or at work.

Items 13-a-f. — Residence of Decedent
Residence of the decedent is the place where he or she actually resided. This is not necessarily the same as "home State," or "legal residence." Never enter a temporary residence such as one used during a visit, business trip, or a vacation. Place of residence during a tour of military duty or during attendance at college is not considered as temporary and should be considered as the place of residence.

If a decedent had been living in a facility where an individual usually resides for a long period of time, such as a group home, mental institution, nursing home, penitentiary, or hospital for the chronically ill, report the location of that facility in items 13a through 13f

If the decedent was an infant who never resided at home, the place of residence is that of the parent(s) or legal guardian. Do not use an acute care hospital's location as the place of residence for any infant

Items 23 and 31 — Medical Certification
The PRONOUNCING PHYSICIAN is the person who determines that the decedent is legally dead but who was not in charge of the patient's care for the illness or condition which resulted in death. Items 23a through 23c are to be completed only when the physician responsible for completing the medical certification of cause of death (Item 27) is not available at time of death to certify cause of death. The pronouncing physician is responsible for completing only items 23 through 26.

The CERTIFYING PHYSICIAN is the person who determines the cause of death (Item 27). This box should be checked only in those cases when the person who is completing the medical certification of cause of death is not the person who pronounced death (Item 23). The certifying physician is responsible for completing items 27 through 32.

The PRONOUNCING AND CERTIFYING PHYSICIAN box should be checked when the same person is responsible for completing Items 24 through 32, that is, when the same physician has both pronounced death and certified the cause of death. If this box is checked, items 23a through 23c should be left blank

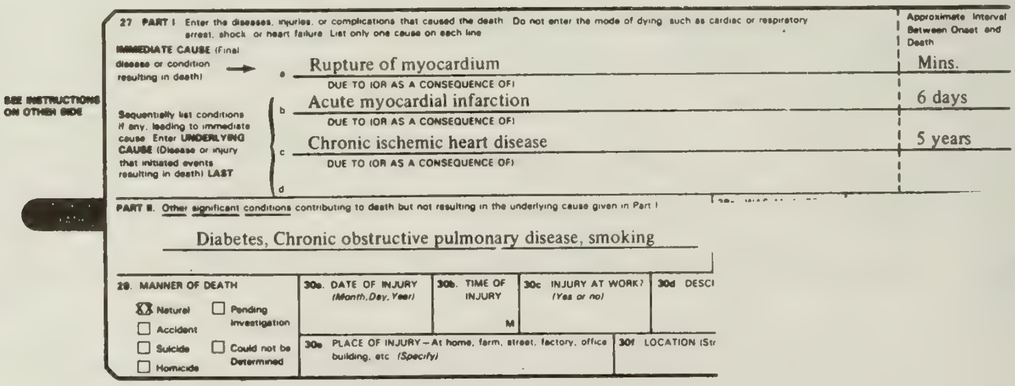
The MEDICAL EXAMINER/CORONER box should be checked when investigation is required by the Post Mortem Examination Act and the cause of death is completed by a medical examiner or coroner. The Medical Examiner/Coroner is responsible for completing items 24 through 32.

Item 27. — Cause of Death
The cause of death means the disease, abnormality, injury, or poisoning that caused the death, not the mode of dying, such as cardiac or respiratory arrest, shock, or heart failure.

In Part I, the immediate cause of death is reported on line (a). Antecedent conditions, if any, which gave rise to the cause are reported on lines (b), (c), and (d). The underlying cause, should be reported on the last line used in Part I. No entry is necessary on lines (b), (c), and (d) if the immediate cause of death on line (a) describes completely the train of events. ONLY ONE CAUSE SHOULD BE ENTERED ON A LINE. Additional lines may be added if necessary. Provide the best estimate of the interval between the onset of each condition and death. Do not leave the interval blank; if unknown, so specify.

In Part II, enter other important diseases or conditions that may have contributed to death but did not result in the underlying cause of death given in Part I.

See examples below.



SEE INSTRUCTIONS ON OTHER SIDE

27 PART I Enter the diseases, injuries, or complications that caused the death Do not enter the mode of dying such as cardiac or respiratory arrest, shock or heart failure List only one cause on each line

Approximate Interval Between Onset and Death

IMMEDIATE CAUSE (Final disease or condition resulting in death) → a Rupture of myocardium — Mins.

DUE TO (OR AS A CONSEQUENCE OF)

Sequentially list conditions if any, leading to immediate cause Enter **UNDERLYING CAUSE** (Disease or injury that initiated events resulting in death) **LAST**

b Acute myocardial infarction — 6 days

DUE TO (OR AS A CONSEQUENCE OF)

c Chronic ischemic heart disease — 5 years

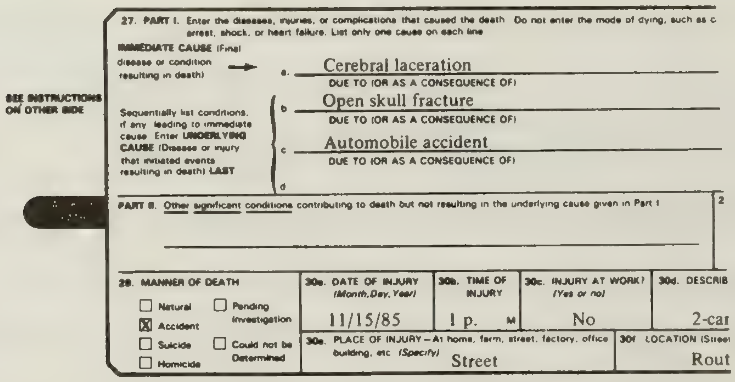
DUE TO (OR AS A CONSEQUENCE OF)

d

PART II. Other significant conditions contributing to death but not resulting in the underlying cause given in Part I

Diabetes, Chronic obstructive pulmonary disease, smoking

28. MANNER OF DEATH	30a. DATE OF INJURY *(Month,Day,Year)*	30b. TIME OF INJURY	30c INJURY AT WORK? *(Yes or no)*	30d DESCI
☒ Natural ☐ Pending Investigation ☐ Accident ☐ Suicide ☐ Could not be Determined ☐ Homicide		M		
	30e PLACE OF INJURY—At home, farm, street, factory, office building, etc *(Specify)*		30f LOCATION (St	



SEE INSTRUCTIONS ON OTHER SIDE

27. PART I. Enter the diseases, injuries, or complications that caused the death Do not enter the mode of dying, such as c arrest, shock, or heart failure. List only one cause on each line

IMMEDIATE CAUSE (Final disease or condition resulting in death) → a. Cerebral laceration

DUE TO (OR AS A CONSEQUENCE OF)

Sequentially list conditions, if any leading to immediate cause Enter **UNDERLYING CAUSE** (Disease or injury that initiated events resulting in death) **LAST**

b Open skull fracture

DUE TO (OR AS A CONSEQUENCE OF)

c Automobile accident

DUE TO (OR AS A CONSEQUENCE OF)

d

PART II. Other significant conditions contributing to death but not resulting in the underlying cause given in Part I

28. MANNER OF DEATH	30a. DATE OF INJURY *(Month,Day,Year)*	30b. TIME OF INJURY	30c. INJURY AT WORK? *(Yes or no)*	30d. DESCRIB
☐ Natural ☐ Pending Investigation ☒ Accident ☐ Suicide ☐ Could not be Determined ☐ Homicide	11/15/85	1 p. M	No	2-car
	30e. PLACE OF INJURY—At home, farm, street, factory, office building, etc *(Specify)* Street		30f LOCATION (Street	Rout

Figure 3

Proposed Change in
MEDICAL CERTIFICATION
of CAUSE OF DEATH

27.	Underlying Cause-List single most important disease/injury which initiated events resulting in death: a.	Interval Between Onset and Death
Part I.	b. Resulting conditions in sequence of occurrence:	
	c. Resulting in:	
	d. Immediate Cause:	
Part II.	List other significant conditions contributing to death but not related to cause(s) given in Part I:	

RESEARCH IMPLICATIONS OF CHANGES IN THE 1989 REVISION OF THE U.S. STANDARD CERTIFICATE OF DEATH IN THE AGING POPULATION

J. David Curb, Toni P. Miles, Lon R. White

In their deliberations, the group overseeing the upcoming revision of the U.S. Standard Death Certificates emphasized the importance of understanding who the major users of vital statistics data will be during the 1990's and the types of issues with which these users will be concerned (NCHS, 1986). In retrospect, we find few issues related to the "graying of America" among their listed concerns.

The changes to the death certificate can be divided into two groups according to their relationship to the cause(s) of death. Those not directly associated with cause of death include:

items 13a-13f: residence
14: Hispanic origin
15: race
16: education

Changes more directly associated with determination of cause of death include:

27, part II: other contributing condition
31a-31d: information on the certifier, including license number
32: identification of the person who completed item 27, cause of death

One prominent example of the impact of these revisions involves the possible utility of the newly added education item for research on socioeconomic status and mortality. On the current certificate, only residence, race, occupation and industry have utility as socioeconomic indicators. Education level, perhaps more than any other single indicator, has been used to define socioeconomic strata. It allows easy classification, has a natural order, and is probably relatively accurately reported in most situations. An important issue to be examined is the validity of education as it will be recorded on the revised death certificate. We will need to know how closely educational attainment as reported by a proxy respondent corresponds with education as it might have been reported by the decedent himself. If correspondence is not very high, we must learn what factors influence the degree of correspondence between proxy- and self-reported education. There is currently little information available bearing on the validity of proxy-reported educational attainment. Nonetheless, the addition of an item on education will greatly facilitate research directed toward understanding the role of socioeconomic factors in mortality, and on the mechanisms which underlie observed differences in health, morbidity, and mortality among different ethnicities and races. Future advancements in the development of socioeconomic measures employed in analyses of mortality data from death certificates will certainly center on education, occupation, and indices derived from these variables.

Race has been a standard feature on the death certificate since 1900 (NCHS, 1983). Although the decedent's ancestry has been asked for in a few states in the past, the 1989 certificate will be the first on which the item is recommended nationwide. It should be noted that a primary objective is to collect data on Hispanics. The Death Certificate Subgroup did not initially recommend this item for inclusion on the standard certificate, their lack of enthusiasm being related to several issues. They anticipated problems with standardization of definitions and expressed concern that the death certificate may not be an appropriate vehicle for primary collection of such data. It was also pointed out that while some states still have little ethnic diversity, ethnic subgroups other than Hispanics are also important and increasing in number in our population. The Death Certificate Oversight Group subsequently added a general item on ancestry, which then evolved into the Hispanic origin question, item 14.

A crucial assumption in studying mortality rates is that the numerators and the denominators refer to the same people; i.e., the denominator must represent the base population from which the "cases" (numerator count) are derived. In the discussion thus far we have delt with problems related to the ethnicity of decedants, i.e., the numerator "case" count for calculation of rates. A corresponding problem exists for determination of ethnicity for denominator counts. For denominators we ordinarily use the most current population estimates or counts, usually as provided by the Bureau of the Census. Although Vital Statistics and U.S. Census sources are likely to agree on the operational definitions and measurement of most demographic variables, substantial differences may occur related to race and ethnicity. The problems underlying such differences might be illustrated by a hypothetical woman named Chavez, whose maiden name was Jones, who speaks Spanish at home in the Los Angeles barrios, but who is genetically of little or no Hispanic ancestry. In addition to such definitional problems, one can also imagine many practical difficulties encountered in collecting reliable data on ethnicity. The type and extent of definitional problems which may be encountered in future studies will reflect how questions of race and ethnicity are asked on the 1990 census forms, as compared with the race and ethnicity items on the death certificate.

Differential mortality among persons of differing ethnicities remains a very important and poorly understood problem. One commonly employed ethnicity classification method identifies individuals as Hispanic on the basis of Spanish surname without regard to ancestry. As suggested by the illustration mentioned above, this approach has many limitations, not the least being problems related to definition of ethnicity for denominator figures. Nonetheless, the 1989 death certificate changes will allow further refinement of the method by allowing a surname classification system for decedants to be combined with information generated by the separate questions on Hispanic origin and race.

The meaning of ethnic self-identification data among Hispanic persons appears to have changed during recent years, persons today being more likely to report themselves as Hispanic than ten to fifteen years ago. This is thought to be related to a decreasing social liability associated with being Hispanic. The influence of this change on mortality rates has not yet been examined, since data for definition of ethnicity have been so limited.

Another factor which could potentially influence our ability to calculate accurate death rates for Hispanic and other ethnic groups is the dropping of the question of citizenship in the new version of the death certificate. It is conceivable that differential reporting of alien status in the census and on death certificates, as might occur as a result of fear of detection of illegal residence, could affect our numerator and denominator counts.

Another major group of new items will facilitate record linkage and enhance computer analyses. These numeric identifiers include the zip code of residence (item 13f), and the license number of the certifying physician (item 31c). Through machine linkage with other computer files, analysis of geographic variation by units as small as zip code areas will improve our ability to examine associations of mortality with environmental, economic, sociocultural, and other factors. Availability of the certifying physician's license number should enhance the investigator's capability to conduct a variety of follow-back studies requiring contact with the family or other care providers.

A number of format changes have been made in an attempt to improve data quality. For example, items concerning the place and manner of death are now presented in a check box format. This change is expected to produce data which is more standardized and consistent.

For some items comparability of data between time periods will have to be considered. One example of this is the data on autopsies, collected since 1949 (NCHS, 1983). The question on use of autopsy findings in determining the cause of death has a more varied past. It was added first in the 1969 version, then dropped in the 1978 revision, and is now added again. If one uses such data in an analysis, these changes must be taken into account.

The value of some new items will be somewhat limited by the likelihood they will not be provided on NCHS public use tapes. Mortality data files include a detail file, a local area summary file, and a cause of death summary file. Concerns related to confidentiality restrict certain information on these tapes, including personal names, addresses, and certificate numbers. Release of data files from localities of less than 100,000 population size is precluded because of the possibility of identifying individuals on the basis of other characteristics.

Not all of the newly collected data will be added to future public use mortality data files. Those variables which will probably be on the tape are Hispanic origin (item 14), race (item 15), and education (item 16). Those which are not likely to be on the mortality data tapes include the city of birth (item 7), place of death (item 9a), zip code of residence (item 13f) and license numbers of the certifying physician (item 31c). One of the most useful of these would be the zip code, since computer linkage with other data files related to local studies would then become feasible. However, the possibility of linking mortality files with local data files for rural areas and small towns is likely to constrain the release of zip codes for deaths.

The planned changes which were designed to increase the accuracy of the cause of death and data surrounding it include:

- availability of autopsy findings, item 28b (this is expected to facilitate an appraisal of the certainty of the diagnosis)

- separate signatures of pronouncing and certifying physicians, item 23a (this separates the institution's need to comply with legal requirements for pronouncement of death from medical issues related to cause of death)

- instructions on the back of the certificate added to increased physician education

The usefulness of the death certificate in Geriatric epidemiology depends to some degree on the particular condition of interest. Although the elderly are at much greater risk for dying than are younger persons, death certificate information is often not very useful for epidemiologic research on many of their common and disabling illnesses. Cause of death may be very difficult to establish in older individuals, since they often have several potentially lethal conditions at the time of death, all of which may have contributed in some degree to the demise. Indeed some have used this fact as rationale for recommending a return to coding of certain deaths as due to natural causes or old age.

Certain highly lethal diseases such as myocardial infarction, stroke, certain malignancies, and terminal infections are relatively unambiguous causes of death. A great deal has and can still be learned about these conditions through death certificate studies. On the other hand, death certificate information is rarely useful for the study of such common and disabling conditions as presbycusis, vision impairments associated with macular degeneration or cataract, angina, TIA's, osteoarthritis, osteoporosis, diverticulosis, or peripheral vascular disease.

With improvements in the completeness and accuracy of cause of death information, there is an intermediate class of conditions for which the death certificate may well become a source of useful information for epidemiologic analysis. These tend to be age-dependent disease, in that their incidence and prevalence increase dramatically and continuously with age. Although they are generally irreversible, they rarely cause death directly; instead, they debilitate the older person, increasing the likelihood of death from causes such as aspiration pneumonia, decubitus ulcer, and septicemia.

One such condition is dementia. Since the most common dementing illnesses are irreversible, every person who develops one of these diseases will have it at death. Nonetheless, our impression is that only 1/5 to 1/10 of the persons diagnosed as demented during life have had a diagnosis implying dementia recorded on the death certificate. Further, it appears that whether or not a diagnosis of dementia is recorded at death reflects secular and temporal variations in style and medical training. The addition of a new line (item 27, part II) for recording "other significant conditions contributing to death..." together with a growing recognition of dementia as a legitimate diagnosis even at very advanced ages, may go far to improve ascertainment of dementia at death. Concurrent improvements in coding of dementia with the tenth revision of the International Classification of Disease, and improvements in information useful for follow-back studies, will enhance the utility of the death certificate for such studies. If death certificate diagnosis of dementia becomes more complete and more uniform, and if variability becomes more random, such data might well be employed to address the following very important questions:

- Does the prevalence of dementia at death vary with ethnicity, lifetime occupation, or geographic location?
- Is the prevalence of dementia at death changing?
- Are there meaningful associations between dementia at death and other conditions listed on the death certificate?

While the changes on the 1989 Revision of the Standard Death Certificate are limited, there are a number of potentially important gains for researchers. The item on education, which can be used as a proxy variable for socioeconomic status, is probably the most significant addition. An increased emphasis on the accuracy of cause of death data through increased physician education, has potential for significantly improving data quality. Other changes, while less important to the geriatric epidemiologist, promise improvements in data quality and present new opportunities for other researchers.

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Mortality Research on Hispanics: Challenges and Opportunities

by

Leobardo F. Estrada
Graduate School of Architecture
and Urban Planning
University of California,
Los Angeles

Introduction

The U.S. Standard Certificate of Death for the 1990's introduces the Hispanic origin item which states, "WAS DECEDENT OF HISPANIC ORIGIN? (Specify No or Yes--If Yes, specify Cuban, Mexican, Puerto Rican, etc.)" Space is provided on the form to check off "yes" or "no" and to write in the origin group. The decision to include this item was not without considerable debate. Some felt that this item would have questionable validity, particularly in the death certificate which would rely on informant reporting. Others felt that the need to understand race and ethnic mortality differences balanced out the data limitations.

At the risk of overgeneralizing somewhat, the major significance of mortality and morbidity analysis is in establishing differential patterns. That differing life styles --and cultural differences-- effect mortality outcomes is an empirical fact. The first empirical study of Hispanic mortality was published less than thirty years ago by Ellis for a study of 1949-51 mortality trends in Houston, Texas (Ellis, 1959). Ellis' results showed differences in crude death rates for Hispanic Spanish Surname and other Whites. Ellis replicated the study in San Antonio, Texas and found similar differences (Ellis, 1962).

Since these seminal studies, Latino--non Latino differentials have been further specified particularly during the last decade (Bradshaw and Founer, 1978; Roberts, 1972). Most of these studies have several common elements. Firstly, all rely upon some Spanish surname measure. Secondly, most of the studies have analyzed Southwestern cities, particularly Houston and San Antonio, Texas. Finally, infant mortality has received undue attention to other issues (Teller and Clyburn, 1974; Powell-Griner and Streck, 1982).

Brief Overview

Burris and Bradshaw's study of Houston, Texas mortality trends for 1958-1960 identified post neonatal rate differentials which were expected. Hispanic rates were close to Black rates in Texas, and they coincided with known associations between SES and post neonatal death rates. Surprisingly, infant mortality rates were closer to Anglo rates than Blacks in Texas. For Latinos in Texas not to have higher IMRs was unexpected (Bradshaw and Founer, 1978). In 1975, Gee reanalyzed the Burris and Bradshaw data and identified birthweight as the explanatory variable predicting the IMRs (Gee, et al., 1976).

Since then, the lower than expected IMRs for Spanish surname persons has gained the attention of researchers who have established the fact that Latino excess mortality in post neonatal rates are associated with lower neonatal rates (Powell-Griner and Streck, 1982). The significance of birthweight as the explanatory variable shifted to the possibility of reporting errors along the U.S.--Mexico border but findings along the South Texas Valley were unable to prove that unrecorded deaths were a major factor. Thus, attention was drawn back to the issue of birthweight and prenatal care.

These early studies decomposing mortality by ethnicity (using Spanish surname) revealed significantly distinct patterns. Nonetheless, ethnic morbidity differentials remain largely unspecified. For example, no studies exist for the aging population, for most parts of the U.S., or comparative studies of the major Hispanic subgroups. The more recent studies point to some exciting possibilities.

Bradshaw analyzed Spanish surname trends for Texas and found higher incidence for infectious and parasitic diseases and diabetes mellitus as well as lower incidence for ischemic heart disease, and for total neoplasms (Bradshaw, 1978). Suarez and Martin (1987) analyzed Texas mortality data for 1969-1980 and identified primary liver cancer rates for Mexican Americans at least two times higher than for other Whites. This differential was intensified for older Mexican Americans. The researchers note that the epidimiological literature usually find that liver cancers are associated with cirrhosis. However, recent surveys do not find significantly different patterns of alcohol intake among Mexican Americans, thus leading them to consider the possibility of other risk factors associated with liver cancer such as hepatitus B infection, aflatoxin, and pesticide exposure. In a related study by the same researchers, they found that cancer mortality was 25 percent lower for Mexican American males (only four percent lower for Mexican American females). This reduced mortality was primarily the result of lower rates for cancers of most common sites: lung, colon, breast and prostate. But higher rates than for whites were found for cancers of stomach, liver, and gallbladder. Mexican American females had higher mortality risk for cervical cancer (Martin and Suarez, 1987).

Information for Health Planners

The findings noted above illustrate the significance of ethnicity as an essential control variable. These ethnic differences have important implications for health planners who need this type of information to ameliorate these trends. It is difficult for a health planner to act on this information without the knowledge of the extent to which these trends derived from Texas data can be generalized to other regions. For that matter, health planners must concern themselves with data based on Spanish surnames which can be changed legally or through marital exogamy (Murguia and Frisbie, 1977).

Health data based on surnames have proven useful and are the only possible method to conduct historical analysis on Latinos using administrative records (Schoen and Nelson, 1981). However, surname based data are difficult to compare when differents lists have been used and second and third generations are likely to be under represented since the most acculturated are most likely to marry out. The most serious limitation of surname based data is the lack of denominator data for surnames. Such data exists mostly for the five Southwestern states and only for decennial years. As a result, surname based data is biased toward high density Hispanic areas (Gillespie, et al., 1983).

Self reporting is the method used for ethnic and racial categorization by the U.S. Census Bureau and also the 1990 Standard Certificates. As mentioned earlier, for death certificates the ethnic racial items will be reported by the next of kin and in a few cases by the funeral director or medical examiner. Powell-Griner (1982) compared surname and self reporting data and separated the primary problems into three categories: a) overreporting of Spanish origin on census (too large a denominator leading to underestimation); b) underreporting of Spanish origin on death certificates by attending physicians (too small a numerator also leading to underestimation); c) combinations of both errors. The extent of these problems are unknown but it serves to establish a beginning for the research studies which must be undertaken early on in the 1990s.

The Challenges and Opportunities

Many of the challenges which confront health researchers in the 1990s are methodological in nature. There is an immense amount of analysis which needs to be conducted to understand the reliability and validity of the new Spanish ethnic item. The need also exists to link the emerging data which will become available in the 1990s to the past studies based on Spanish surname to determine changes in trends due to the shift to self reporting/informant reporting data.

There are other challeges for researchers as well. Most researchers for example assume they are working within a closed record system and thus if needed, they can conduct follow back studies of death certificate records to other vital event records. However, given the high proportion of immigrant persons within the Latino population, it will often be the case that the birth, marriage, and divorce records will be located outside this country's borders.

The opportunities for health researchers are exciting. For one, standardization of the ethnic item creates the posssibility of comparative regional studies for significant Latino areas which have never been studied such as the New York metropolitan area, South Florida, the Chicago metropolitan area, etc. Additionally, analysis of the national level data will provide the baseline information required for national attention to those health issues with require national level efforts by health policy decision makers.

Conclusion

The analysis of health data generally moves from the calculation of crude rates to age and sex specific rates in an effort to refine our knowledge of the incidence and prevalence of health outcomes. When the data are available, further refinements are made using race and education variables. In light of this, the availability of Hispanic origin data on a national level is a rational extension of the type of data which has a demostrated ability to predict health outcomes. The availability of Hispanic origin data opens up the opportunity to reestablish the association between ethnicity/race and mortality. Existing data for the White population will be affected by the introduction of the Hispanic origin item as the White rates are further decomposed. The results may be confusing at first but in the long run, the ethnic racial differentiation will result in better targetting, health programming and utilization of the health delivery services.

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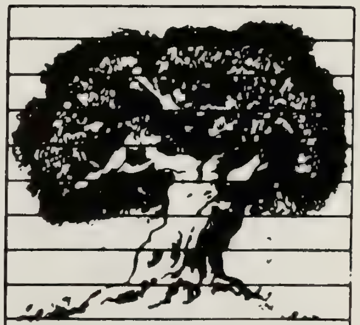
Session BB

Changes in Approaches to the Delivery of Health Care



DATA FOR AN AGING POPULATION

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MENTAL HEALTH ORGANIZATION DATA ON MENTAL HEALTH SERVICES TO THE ELDERLY

Michael J. Witkin and Ronald W. Manderscheid,
National Institute of Mental Health

Various estimates from the National Institute of Mental Health and elsewhere show that between 10 and 28 percent of older Americans (65 years and over) living in the community have mental disorders serious enough to warrant some form of mental health care. This represents 2.6 to 7.3 million elderly Americans. Mental disorders are generally more prevalent in the 65-74 age group, while cognitive impairment is more prevalent among those age 75 and over. Rates are higher for females than for males.

Only 892,035 persons (3.2 percent of the elderly population) were institutionalized in 1983. Of these, virtually all were either in nursing homes (96 percent) or State mental hospitals (3 percent). Of the 855,035 in nursing homes, 65 percent had a diagnosis of cognitive impairment or other mental disorder.

With the exception of inpatient and residential treatment programs, the elderly are represented in the caseload of mental health services in all types of organized specialty settings relatively less than are adults in the 18-64 age group. However, the rates for the 65 year and over group are higher than those for children and youth in all three settings.

These findings were derived from information collected through the biennial 1983 Inventory of Mental Health Organizations. The Inventory was sent by the Survey and Reports Branch, National Institute of Mental Health, to all specialty mental health organizations in the United States, except general hospital psychiatric services. One question asked for the distribution of the caseload at the end of the reporting year by broad age groups (less than 18, 18-64, 65 and over) for each type of program operated (inpatient and residential treatment, outpatient, and partial care).

The 1983 caseload rates per 100,000 civilian population, by type of program and age group, are as follows:

Age group	Type of Mental Health Program		
	Inpatient and residential treatment	Out-patient treatment	Partial care
	Caseload rate per 100,000 civilian population		
All ages	84.3	71.6	1,066.3
Under 18 years ..	50.4	31.3	750.4
18-64 years	91.5	93.3	1,229.0
65 years and over	125.2	51.3	944.7

While the rate for the elderly greatly exceeded those for the other age groups in inpatient and residential treatment programs, the rates for the elderly in outpatient and partial care programs are substantially lower than for other adults but higher than for children.

Medicare enrollment in Health Maintenance Organizations

Alma McMillan, James Lubitz, Ronald Prihoda,
Lynne Rabey, Delores Russell

INTRODUCTION

Changes in reimbursement policies for health maintenance organizations (HMOs) and competitive medical plans (CMPs) under the Tax Equity and Fiscal Responsibility Act (TEFRA) of 1982 (Public Law 97-248) stimulated participation of HMOs in Medicare. Nearly a decade ago, the Health Care Financing Administration (HFCA) began sponsoring demonstration projects to test the feasibility of providing health care to Medicare beneficiaries on a capitated basis. It was expected that cost savings as well as expanded access to care would result. HMO participation in Medicare would increase the choices of delivery system for both beneficiaries and providers.

TEFRA provisions are intended to reduce the cost of delivering Medicare covered services to risk HMO enrollees by at least by 5 percent. Under TEFRA, HMOs are paid a prospectively determined amount for risk enrollees (without retroactive adjustment). This amount is equal to 95 percent of the projected costs of care for beneficiaries in the local fee-for-service market. TEFRA also provides for cost contracts with HMOs, in which case, HMOs are paid for reasonable costs up to 100 percent of the prospectively determined amount.

SOURCES OF DATA

Data for this study were derived from HCFA files containing information on overall Medicare enrollment, on enrollment in HMOs, and on the characteristics of HMOs with Medicare contracts. Data on HMO enrollment of the general population came from InterStudy, a private organization which collects and disseminates information about the HMO industry.

FINDINGS

Enrollment by type of beneficiary

The growth in Medicare HMO enrollment during the period 1984 to 1986 indicates that TEFRA provided the incentives needed to encourage the elderly to enroll in capitated health care plans. Data in Table 1 show that the overall Medicare HMO enrollment increased from an average annual enrollment of 304,196 in 1984 to 859,476 in 1986 or an increase of 182.5 percent. Enrollees under risk contracts rose from 211,286 to 716,142, an increase of 238.9 percent during that period, while those under cost contracts rose from 92,910 to 143,330, an increase of 54.3 percent. The majority of Medicare HMO enrollees (96.1 percent in 1986) were aged persons and the remainder (3.9 percent) were disabled and end-stage renal disease (ESRD) enrollees (Table 2). Among the general Medicare population a somewhat smaller proportion was aged (90.8 percent) and the remainder was disabled and ESRD persons. The distribution of risk enrollees showed little change since the TEFRA legislation.

Geographic area

The following analysis will focus primarily on aged risk enrollees. The data in Tables 3 and 4 show the geographic distribution for aged Medicare HMO enrollees and the general Medicare population. Enrollees under risk contracts in the West grew from 46,543 in 1984 to 212,521 in 1986, or from 1.0 percent of the Medicare population in that area to 4.4 percent. The Northeast region had the least number of risk enrollees in 1984, 16,634 or 0.3 percent of the Medicare population but rose to 89,872 enrollees, accounting for 1.4 percent of the Medicare population (Table 3).

The largest proportion (33.2 percent) of the general aged Medicare population in 1986 was in the South and the smallest proportion (17.6 percent) was in the West. By comparison, the largest proportion (31.1) of aged Medicare risk enrollees was in the North Central and the Northeast had the smallest (13.1 percent) (Table 4). Before TEFRA (1984), however, the largest proportion (44.0 percent) of aged risk enrollees was in the South. This shift in the geographic distribution of Medicare HMO enrollees highlights the growth in the number of risk enrollees since TEFRA in the North Central region and also in the West.

Table 5 shows the penetration of HMO enrollees and Medicare risk enrollees by State in 1987. Nationally, 10.6 percent of the U.S. population is enrolled in an HMO compared with 3.1 percent of Medicare beneficiaries in TEFRA risk plans. Twenty States had an HMO penetration rate near or greater than the national average of 10.6 percent. Only three States had an HMO penetration rate greater than 10 percent among Medicare beneficiaries. In two of the four States with the highest HMO penetration rates in the general population (California and Wisconsin), the Medicare HMO penetration rates were much lower. In the two other States (Minnesota and Hawaii), the Medicare HMO penetration rates actually exceeded the HMO penetration rates of the general population.

Table 6 compares the age, sex, and race distribution of the general Medicare population with that for aged Medicare risk HMO enrollees. There are several noteworthy observations in comparing these distributions. First, in 1986 the proportion of enrollees 65-69 years of age was about the same (31.8 percent versus 31.4 percent) for both the general Medicare population and the Medicare risk HMO enrollees. Second, the proportion of enrollees 70-79 years of age was greater among risk HMO enrollees than the general Medicare population (49.9 percent versus 45.6 percent). Third, although the proportion of enrollees 80 years and over was smaller among risk HMO enrollees than the general Medicare population (18.7 percent versus 22.7 percent), it appears that TEFRA legislation has encouraged risk HMO enrollment for persons in the older age groups. Fourth, the male/female ratio for risk HMO enrollees is similar to that for the general Medicare population. Finally, the proportion of minorities enrolled in Medicare risk HMOs was somewhat smaller than that for the general Medicare population.

HMO characteristics

Tables 7 through 11 provide information on enrollment by HMO characteristics. The data in Table 7 show the number of risk plans and enrollees by period contract was signed as of June 1987. Of the 49 plans signed April-June 1985, most were demonstration projects or cost contracts converting to risk. Only 14 of the 49 plans were new contracts. During the period

July-December 1985, 50 risk contracts were signed, 36 of which were first-time contracts. Entry of new plans slowed after the first 12 months of the TEFRA but enrollment continued to grow at a rather rapid pace, especially in "old" plans. As of June 1987, 60.5 percent of Medicare risk enrollees were in the original 49 plans signing contracts in April-June 1985.

Tables 8A and 8B show the largest HMOs. As of June 1987, the 5 largest risk HMOs accounted for 37.1 percent of all Medicare risk enrollees. Humana of Florida (formerly International Medical Centers of Florida) was by far the largest with over 115, 000 enrollees. Medicare risk enrollees in these five HMOs were 41.8 percent of their total enrollment; Humana's 115,000 Medicare enrollees represented 66.6 percent of its total enrollment (Table 8A).

The five largest national HMOs (Table 8B) accounted for 21.9 percent of HMO enrollees, of which Kaiser Foundations in Northern and Southern California ranked first and second. Only one of the 5 largest HMOs have Medicare risk enrollees--HMO of Pennsylvania. (Kaiser Foundation Health Plan, Southern California signed a risk contract in June 1987.)

HMOs have several types of organizational arrangememts for delivering health care services. Table 9 shows that of the four current types of arrangements, there are more independent physician association (IPA) models (with more enrollees) than any other model. For all HMOs, IPAs accounted for 38.6 percent of enrollees and 61.7 percent of the number of plans. For Medicare HMO enrollees, IPAs accounted for 57.2 percent of risk enrollees and 63.0 percent of plans. Groups models ranked second with 26. 5 percent of all HMO enrollees and 29.4 perecent of Medicare risk enrollees. Network models ranked third among all HMOs with 23.3 percent of enrollees, however, there were no risk network models. In December 1986, there were 8 network models, however, by June 1987, 6 had become IPA models and 2 no longer had risk contracts. Staff models had the smallest proportion of enrollees--11.6 percent for all HMOs and 13.4 percent of Medicare risk enrollees.

The number of HMOs and enrollees by profit status are shown in Table 10. Of the 626 HMOs, in December 1986, 389 or 62.1 percent were for-profit and their enrollees represented 41.6 percent of total enrollees. In comparsion, for Medicare risk plans, a much smaller proportion, 42.2 percent, were for-profit and accounted for 43.5 percent of Medicare risk enrollees.

Data for June 1987 showed that all risk HMOs offered additional benefits beyond Medicare covered services. Of the 154 risk plans, 135 or 87.7 percent offered hospital days beyond Medicare coverage and 132 or 85.7 percent of plans offered preventive care. Nearly three-quarters of enrollees were in plans that offered additional hospital days and nearly 85 percent were in plans that offered preventive care (Table 11).

In summary, the data presented showed that:

(1) There has been rapid growth in Medicare HMO enrollment since TEFRA legislation was implemented.

(2) California and Wisconsin had high penetration rates in the general population, but relatively low rates among Medicare enrollees. On the other hand, the penetration rates in the Hawaii and Minnesota were high in both the general and Medicare populations.

(3) Of the five largest HMOs, three of which are among the oldest in the country, four had no TEFRA risk enrollees.

(4) IPA model HMOs accounted for more than half of all Medicare risk enrollees.

(5) About 60 percent of Medicare risk enrollees were in the original 49 plans signing contracts in the period April-June 1985.

(6) Most Medicare risk HMOs offered hospital days beyond Medicare coverage and most also offered preventive care.

Thus, it appears that TEFRA legislation has indeed become the stimulus for increased Medicare participation in prepaid capitation plans.

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Table 1 - Number of Medicare HMO enrollees by type of beneficiary, 1984 and 1986

Type of beneficiary	1984	1986	Percent change 1984-86
Total	304,196	859,476	182.5
Aged	290,985	826,097	183.9
Disabled	12,820	32,781	155.7
ESRD	391	598	52.9
Risk	211,286	716,142	238.9
Aged	202,691	688,117	239.5
Disabled	8,455	27,705	227.7
ESRD	140	320	128.6
Cost	92,910	143,330	54.3
Aged	88,294	137,980	56.3
Disabled	4,365	5,076	16.3
ESRD	251	277	10.4

Source: Bureau of Data Management and Strategy, Health Care Financing Administration

Table 2 - Number and percent distribution of Medicare enrollees and Medicare HMO risk enrollees by type of beneficiary. 1984 and 1986

Type of beneficiary	Medicare enrollees July 1, 1986 1/	Medicare HMO risk enrollees 1984	1986
Total	30,535,070	211,286	716,142
		Percent	
Aged	90.8	95.9	96.1
Disabled	9.1	4.0	3.9
ESRD	0.1	0.1	--

1/Estimated hospital insurance enrollees, U.S.
-Less than .05

Source: Bureau of Data Management and Strategy, Health Care Financing Administration

Table 3 - Aged Medicare risk HMO enrollees by geographic region, 1984 and 86

Geographic region	1984 Number of HMO enrollees	1984 Percent of total Medicare population	1986 Number of HMO enrollees	1986 Percent of total Medicare population
Total U.S.	202,690	0.8	688,117	2.5
Northeast	16,634	0.3	89,872	1.4
North Central	50,383	0.7	213,993	3.0
South	89,130	1.0	171,732	1.9
West	46,545	1.0	212,521	4.4

Source: Bureau of Data Management and Strategy, Health Care Financing Administration

Table 4 - Number and percent distribution of aged Medicare enrollees and aged Medicare HMO risk enrollees by geographic region, 1984 and 1986

Geographic Region	Medicare enrollees July 1, 1986 1/	Medicare Risk HMO enrollees 1984	Medicare Risk HMO enrollees 1986
Total U.S.	27,711,700	202,691	688,117
		Percent	
U.S.	100.0	100.0	100.0
Northeast	23.2	8.2	13.1
North Central	25.9	24.9	31.1
South	33.2	44.0	25.0
West	17.6	23.0	30.9

1/Estimated hospital insurance enrollees, U.S.

Source: Bureau of Data Management and Strategy, Health Care Financing Administration

Table 5 - Percent HMO enrollees of total U.S. population and percent TEFRA risk enrollees of total Medicare enrollment, 1987

State	HMO enrollees as percent of population 1/	TEFRA risk enrollees as percent Medicare enrollees 2/	State	HMO enrollees as percent of population 1/	TEFRA risk enrollees as percent Medicare enrollees 2/	State	HMO enrollees as percent of population 1/	TEFRA risk enrollees as percent Medicare enrollees 2/
U.S.	10.6	3.1						
Alabama	2.4	0.0	Maryland	10.2	0.7	South Carolina	5.2	0.0
Alaska	0.0	0.0	Massachusetts	18.1	7.1	South Dakota	0.4	0.0
Arizona	15.3	2.0	Michigan	11.6	4.0	Tennessee	3.8	0.8
Arkansas	0.9	0.0	Minnesota	20.6	30.5	Texas	5.2	0.3
California	25.0	6.6	Mississippi	0.0	0.0	Utah	14.3	0.0
Colorado	13.6	7.8	Missouri	8.4	0.1	Vermont	1.3	0.0
Connecticut	10.1	0.9	Montana	0.0	0.0	Virginia	4.7	0.0
Delaware	10.4	0.0	Nebraska	3.6	1.7	Washington	9.4	0.0
Dist. of Col. 3/	50.0	0.0	Nevada	11.5	14.5	West Virginia	2.2	0.0
Florida	8.7	8.9	New Hampshire	10.2	0.0	Wisconsin	21.5	0.4
Georgia	4.8	0.0	New Jersey	8.0	1.5	Wyoming	0.4	0.0
Hawaii	19.1	22.4	New Mexico	9.6	9.8			
Idaho	0.1	0.0	New York	10.4	1.0			
Illinois	11.7	3.4	North Carolina	4.8	0.1			
Indiana	6.5	1.9	North Dakota	5.6	0.4			
Iowa	6.2	0.7	Ohio	10.4	0.4			
Kansas	6.8	3.9	Oklahoma	4.5	1.2			
Kentucky	3.8	0.0	Oregon	17.6	9.7			
Louisiana	2.8	0.0	Pennsylvania	7.7	1.1			
Maine	0.2	0.0	Rhode Island	16.4	2.5			

/Based on information from The Interstudy Edge.

2/Based on information from the Office of Prepaid Health Care, Health Care Financing Administration.

3/HMO enrollment is assigned to States according to location of plan. Thus, the high percent of HMO enrollment in the District of Columbia represents an artifact of the data. Several HMOs having main offices in the District of Columbia have members living in the neighboring States of Maryland and Virginia.

Table 6 - Number and percent distribution of Medicare enrollees and Medicare HMO risk enrollees by age, sex, and race, 1984 and 1986

Age, sex and race	Medicare enrollees July 1, 1986 1/	Medicare Risk HMO enrollees 1986
Total	28,265,650	688,117
	Percent	
Total	100.0	100.0
Age		
65-69	31.8	31.4
70-79	45.6	49.9
80+	22.7	18.7
Sex		
Men	40.3	42.8
Women	59.7	57.2
Race		
White	88.1	89.9
Black	8.9	5.2
Other		2.5
Unknown	3.0	2.3

1/ Estimated hospital insurance enrollees, all areas

Source: Bureau of Data Management and Strategy, Health Care Financing Administration

Table 7 - Number and percent of TEFRA risk plans and enrollees by period contract signed, June 1987

Period contract signed1/	Number of plans	Percent	Number of enrollees	Percent
Total	154	100.0	910,909	100.0
April - June 1985	49	31.8	550,925	60.5
July - December 1985	50	32.5	178,205	19.6
January - June 1986	30	19.5	163,884	18.0
July - December 1986	18	11.7	14,310	1.6
January - June 1987	7	4.5	3,585	0.4

Source: Office of Prepaid Health Care, Health Care Financing Administration

Table 8A - National HMO enrollment, total Medicare risk HMO enrollment, and enrollment in the 5 largest risk plans

HMO	Total HMO enrollment December 1986	HMO Medicare risk enrollees Number June 1987	Percent	Percent Medicare risk of Total HMO
Total	25,777,130	910,909	100.0	3.5
Top 5	808,961	338,360	37.1	41.8
1. Humana Medical Group, Florida	172,973	115,130	12.6	66.6
2. Physicians Health Plan of Minnesota	156,825	61,962	6.8	39.5
3. Family Health Plan, Inc. of California	147,295	58,108	6.4	39.5
4. Pacificare, California	175,568	57,021	6.3	32.5
5. Share, Minnesota	156,300	46,139	5.1	29.5

Source: Office of Prepaid Health Care, Health Care Financing Administration

Table 8B - Total national HMO enrollment and enrollment in the 5 largest plans

HMO	HMO enrollees Number December 1986	Percent	Percent Medicare TEFRA risk enrollees June 1987
Total	25,777,130	100.0	3.5
Top 5	5,645,239	21.9	0.3
1. Kaiser Foundation Health Plan, Northern California	2,016,990	7.8	1/
2. Kaiser Foundation Health Plan, Southern California	1,836,821	7.1	1/
3. Health Insurance Plan of Greater New York	905,940	3.5	1/
4. Health Net - Van Nuys, California	450,228	1.8	1/
5. HMO of Pennsylvania, Blue Bell, Pennsylvania	435,260	1.7	3.5

1/ No TEFRA risk enrollees

Source: The Interstudy Edge, Spring 1987

Table 9 - Number and percent of total health maintenance organizations and Medicare TEFRA risk plans and enrollees by type of model

Type of model	Enrollees		Plans	
	Number	Percent	Number	Percent
Total HMOs[1]	25,777,130	100.0	626	100.0
IPA	9,956,870	38.6	386	61.7
Group	6,822,759	26.5	73	11.7
Staff	2,987,103	11.6	66	10.5
Network	6,010,398	23.3	101	16.1
Medicare TEFRA risk[2]	910,909	100.0	154	100.0
IPA	520,855	57.2	97	63.0
Group	267,867	29.4	33	21.4
Staff	122,187	13.4	24	15.6
Network	--	--	--	--

1/As of December 1986, Source: The InterStudy Edge

2/As of June 1987, Source: Office of Prepaid Health Care, HCFA

IPA -	HMO contracts directly with physicians in solo or group practice.
Group -	HMO contracts predominately with one independent group practice.
Staff -	HMO delivers services through a physician group that is controlled by the HMO.
Network -	HMO contracts predominately with two or more independent group practices.

Table 10 - Number and percent distribution of total health maintenance organizations and Medicare TEFRA risk plans and enrollees by profit status

Profit status	Plans		Enrollees	
	Number	Percent	Number	Percent
All HMOs[1]	626	100.0	25,777,130	100.0
For profit	389	62.1	10,735,498	41.6
Not-for-profit	237	37.9	15,041,632	58.4
Medicare TEFRA risk[2]	154	100.0	910,909	100.0
For profit	65	42.2	395,790	43.5
Not-for-profit	89	57.8	515,119	56.5

1/As of December 1986, Source: InterStudy Edge

2/As of June 1987, Source: Office of Prepaid Health Care, Health Care Financing Administration

Table 11 - Number and percent of Medicare TEFRA risk health maintenance organizations providing benefits in addition to Medicare, and number and percent of enrollees, by type of additional benefit: June 1987

Type of additional benefit	Plans		Enrollees	
	Number	Percent	Number	Percent
Total	154	100.0	910,909	100.0
Extended hospital days	135	87.7	677,355	74.4
Extended SNF[1] days	62	40.3	272,250	29.9
Preventive care	132	85.7	770,744	84.6
Drugs	115	74.7	733,152	80.5
Eye care	114	74.0	703,092	77.2
Ear care	69	44.8	418,131	45.9
Dental care	29	18.8	305,216	33.5
Extended mental health	61	39.6	151,204	16.6
Miscellaneous	66	42.9	512,979	56.3

1/SNF is skilled nursing facility

Source: Office of Prepaid Health Care
Health Care Financing Administration

PROJECTED NEED FOR BOARD AND CARE

Joan Turek-Brezina, Department of Health and Human Services

Board and care is frequently viewed as an alternative to more expensive institutional arrangements for impaired persons who lack the physical capacity and family supports to live independently.[1] Such persons might be frail older persons, the seriously and persistently mentally ill (sometimes called the chronically mentally ill), including the chemically dependent, and persons with mental retardation and other developmental disabilities. The policy importance of board and care is stimulated by a number of concerns:

- A philosophical commitment to in-home and community-based living arrangements—that is, to providing the least restrictive form of care for persons unable to live independently.
- Interest in finding less costly alternatives to institutional care.
- Worry that the future growth of dependent populations, particularly the frail elderly, will create new demands for long-term care that cannot be met by the current system of providing and reimbursing services.
- Fear that the growth of this largely unregulated service will spawn abuse and fraud.

At present information on board and care is largely unavailable. Given the enormous public and private investments in long-term care (more than $30 billion annually) and the demographic and other trends that will govern future long-term care demand, the gap in our knowledge about this key part of the service continuum should be remedied. This paper attempts, in part, to fill this gap by developing estimates of the need for long-term care and for board and care in 1990. Focus is on the demand for these services. Whether sufficient board and care facilities will be available to meet the projected need is not examined.

During the 1980s, the need for long-term care is projected to increase at a significantly faster rate than the total population—with the vulnerable elderly needing such care increasing at the fastest rate. The need for long-term care in a noninstitutional setting is also projected to increase faster than the total population. Significant numbers of these persons—between 4.7 and 5.9 million persons—are projected to be at risk of needing community-based residential care by 1990. Of these persons, an estimated 1.6 to 4.8 million, or 12% to 36% of those estimated to need long-term care in a noninstitutional setting, are projected to need board and care in as many as one-half million to well over one million board and care homes.

NEED FOR LONG-TERM CARE

Since the early 1980s, several demographic factors have contributed to a rapid growth in the need for long-term care services, and toward the increasing need for such services in a noninstitutional setting:

- **The population 65 and older is increasing much faster than the rest of the population.** According to the Census Bureau's mid-range estimates, between 1980 and 1990 the number of persons 65 and older will increase from 11.3% of the population to 12.7%.[2]
- **Within the 65 or older cohort, the population 75 or older is increasing rapidly.** Forty-three percent of the increase in the population 65 and over will be in the number of persons between the ages of 75 and 84. Another 18% will be persons 85 and older.[3]
- **As overall population increases, the total number of developmentally disabled and mentally ill persons will also rise.** The developmentally disabled also are living longer as the result of better understanding and treatment of their medical problems.
- **Trends toward deinstitutionalization have continued unabated.** Aggressive stances taken by mental health, mental retardation and other advocacy groups have resulted in legislation stimulating the development of community-based facilities, class-action suits and the now established legal principle of the right to the least restrictive form of care for those unable to live independently.[4]

Table 1 below provides estimates of the need for long-term care both in total (institutional and noninstitutional settings) and in a noninstitutional setting in 1980 and 1990 taking these demographic factors into account. They are based on projections of the total population developed by the Bureau of the Census. Estimates are provided on the total need for long-term care and on the need for such care in a noninstitutional setting for three separate groups: the vulnerable elderly, seriously and persistently mentally ill and developmentally disabled. Persons are included in the estimates if they experience limitations in activities of daily living, such as difficulty getting around or needing assistance with personal care tasks, sufficient to require some kind of ongoing long-term supportive services.[5] Figures for the seriously and persistently mentally ill and developmentally disabled are for persons under 65 years of age. Persons 65 years or older are identified as vulnerable elderly regardless of the underlying condition creating a need for long-term care.

Table 1

ESTIMATED NEED FOR LONG-TERM CARE: 1980-1990
(000)

A. Estimated Total Need for Long-term Care

	1980	1990	% change
Vulnerable Elderly	5,816	7,582	30%
Seriously and Persistently Mentally Ill	5,129	5,682	11%
Developmentally Disabled	3,030	3,269	8%
Totals	13,975	16,533	18%
Total Population	227,704	249,657	10%

B. Estimated Need for Long-term Care in a Noninstitutional Setting

	1980	1990	% change
Vulnerable Elderly	4,629	5,959	29%
Seriously and Persistently Mentally Ill	4,179	4,632	11%
Developmentally Disabled	2,860	3,141	10%
Totals	11,668	13,732	18%

The projected 10% increase in the total population from 1980 to 1990 is much lower than the projected increase in the number of persons needing long-term care or in the number of persons requiring such care in a noninstitutional setting—both of which are projected to increase by 18%. Vulnerable elderly requiring long-term care are projected to increase at a much faster rate than other vulnerable populations. By 1990, vulnerable elderly persons are estimated to account for 46% of those needing long-term care, seriously and persistently mentally ill persons for 34%, and developmentally disabled for 20%. Over the long run, however, the vulnerable elderly are expected to generate the largest increase in the need for long-term care. By the year 2040, when the "baby boomers" have entered their frail elderly years, there will be an estimated 30 million impaired elderly.[6]

NEED FOR COMMUNITY-BASED RESIDENTIAL CARE IN 1990

At present, there is limited information on the transition from independent living to community-based residential care or institutional care. Many factors appear to play a role in determining who is at risk of needing community-based residential care including degree of impairment, age, type of condition (e.g., mentally retarded), living alone, living with an elderly caretaker or with persons likely to be employed full time outside the home. At the same time, surveys of the elderly indicate their overwhelming preference to remain in their own home and communities. Thus, there are many persons who continue to live at home, yet who possess characteristics similar to those of persons receiving residential care. However, those persons identified as needing long-term care in a noninstitutional setting and with the characteristics listed above can be viewed as being at higher risk of needing community-based residential care.

Estimates of the number of these higher risk persons were developed using information from the Wave 3 supplement of the 1984 panel of the Survey of Income and Program Participation (SIPP). They were developed in two-stages. Initially, persons whose impairments were severe enough to indicate potential problems with living alone were separately identified. In this process, their age and/or type of impairment were taken into account. Two measures were used to identify those persons with impairments sufficient to make independent living difficult.[7] First, persons needing the personal assistance of another person because they had trouble getting around or were unable to do housework or prepare meals are considered to be at risk of needing community-based residential care. Second, those needing the assistance of another person with these activities due to severe functional limitations[8] are considered to be even more at risk of needing such care. Persons indicating they had the activity-of-daily-living limitations described above were also asked what health condition was mainly responsible for their need for personal assistance.[9] This information was used to separately identify seriously and persistently mentally ill and developmentally disabled persons under age 65.

After separately identifying these impaired persons, information on their living arrangements was then used to further identify those most at risk of needing community-based residential care. Those impaired persons identified above who lived alone are assumed to be most at risk of needing community-based residential care. Other persons were also considered to be among those most at risk of needing community-based residential care if they lived with caretakers who are likely to experience difficulty providing such care due to, for example, their also being elderly or employed. Thus:

> **Vulnerable elderly persons** were considered to be at risk of needing community-based care if they live alone or with nonrelatives, live only with their spouse who is also likely to be elderly, live with their spouse and other(s) but not with a son or daughter or live with a related householder other than a son or daughter. Some of the persons who live with nonrelatives are already receiving community-based care. Some of the oldest old are also living with children who are likely to be elderly as well; however, it was not possible to take them into account in this analysis.[10]
>
> **Seriously and persistently mentally ill and developmentally disabled** persons are considered to be at risk of needing community-based residential care if they live alone, with nonrelatives, or if less than 18 years of age they cannot or will not attend regular school.[11] In addition, seriously and persistently mentally ill persons living with spouses only are considered to be at risk of needing community-based residential care since many of these spouses are likely to be employed. Developmentally disabled persons 45 years and older are considered to be at risk of needing community-based residential care if they live with a related householder since these caretakers are likely to be elderly.

Table 2

ESTIMATED NUMBER OF PERSONS MOST AT RISK OF NEEDING COMMUNITY-BASED RESIDENTIAL CARE IN 1990

(000)

A. Needs Assistance of Another Person

	Developmentally Disabled	Seriously and Persistently Mentally Ill	Aged 65-74	Aged 75 +	Cumulative Total
1. Lives alone, with relatives or if less than 18 cannot or will not attend regular school	421	772	347	1,784	3,324
2. Lives with spouse only		240	596	1,143	5,303
3. Lives with spouse and other(s) but not son or daughter			46	51	5,400
4. Lives with related householder other than son or daughter	5		78	403	5,886
As % persons needing non-institutional care	14%	22%	75%	43%	

B. Needs Assistance Due to Severe Functional Limitations

	Developmentally Disabled	Seriously and Persistently Mentally Ill	Aged 65-74	Aged 75 +	Cumulative Total
1. Lives alone, with relatives or if less than 18 cannot or will not attend regular school	181	772	302	1,516	2,771
2. Lives with spouse only		240	203	1,006	4,220
3. Lives with spouse and and other(s) but not son or daughter			41	44	4,305
4. Lives with related householder other than son or daughter	2		64	372	4,743
As % persons needing non-institutional care	6%	22%	60%	35%	

Nearly 6 million persons needing personal assistance, or 43% of those estimated to need long-term care in a noninstitutional setting, are estimated to be most at risk of needing community-based residential care. Nearly 5 million of them, or 35% of those needing long-term care in a noninstitutional setting, are considered to be most at risk because they have severe functional limitations. The majority of those most at risk are elderly—nearly 60% of the elderly have severe functional limitations while 75% need personal assistance. The next largest group is the seriously and persistently mentally ill. Although the developmentally disabled appear to be the smallest group, this figure may significantly understate their need for community-based residential care. This group is composed primarily of mentally retarded persons, many of whom are already in community-based residential care.

These estimates, presented in Table 2, may not be fully representative of those needing community-based residential care. Some persons currently receiving such care are excluded from the SIPP sampling frame, that is, they are classified as in institutional group quarters. The degree to which this occurs cannot be determined. Homeless persons, many of whom are mentally ill, are also excluded from the sample frame.

NEED FOR BOARD AND CARE

Identifying those persons most at risk of needing community-based residential care who will actually end up requiring such care is difficult. Little information exists for explaining the move into community-based residential care or into board and care in particular. For this reason, a range of estimates has been developed of persons projected to need board and care in 1990. Depending upon the factors considered to be important in determining who will enter a board and care home, between 1.6 and 4.8 million persons are estimated to need this service in 1990.

This range of estimates was developed as follows:

> **Help with Difficult Activities:** A recent National Center for Health Statistics report suggests that the ability or inability of the elderly to get help with difficult activities, such as heavy housework, may be an important factor in determining who remains in the community and who enters a nursing home or other institution for needed care and assistance.[12] They found that 19% of persons aged 65 or over living in the community received help with heavy housework as a result of health-related problems in performing that activity. On this basis, an estimated 81% of those persons of all ages at risk of needing community-based residential care, or 3.8 to 4.8 million persons, are estimated to need board and care in 1990.
>
> **Income:** Persons with higher incomes frequently have a wider range of

options available from which to chose. According to information from the Wave 3 supplement to SIPP, 74% of those persons of all ages needing personal assistance with one or more activity had incomes of $1,999 or less per month in 1984. On this basis, 3.6 to 4.4 million persons are projected to need community-based care in 1990.

Access to Support Services: The ability to obtain assistance with difficult tasks may itself be more a function of income level than of degree of disability. That is, persons with higher incomes may pay for the assistance necessary to stay at home. If both factors are important, then 60% of these persons, or 2.9 to 3.5 million persons, are projected to need board and care in 1990.

Current Marital Status: A recent study found that 93.4% of the elderly board and care residents in 5 states were not currently married.[13] According to SIPP, 30.6% of those persons with an activity-of-daily-living limitation were not currently married, while 34.3% of those reporting that these limitations were due to a severe functional limitation were not currently married. On this basis, 1.6 to 1.8 million persons are estimated to need board and care in 1990.

NUMBER OF BOARD AND CARE HOMES NEEDED IN 1990

Translating the estimates of those projected to need community-based residential care in 1990 into precise estimates of the number of board and care homes needed is virtually impossible. While the estimates of those needing long-term care can be developed from Census population projections, estimates of the number of community-based residences in which they reside, including board and care homes, cannot be developed from Census-based information. That is, the Census classification of places identifies institutional and noninstitutional group quarters and housing units. Board and care homes are found in all of these categories and, at present, neither these homes, nor the persons residing in them, can be separately identified. The lack of information on the current supply of board and care homes precludes the development of estimates of their supply in 1990. Fragmentary evidence suggests that board and care homes have experienced rapid growth during the decade of the 1980s and, further, that this growth has been concentrated in small-sized facilities.[14] This information, however, is insufficient for estimating the average size of board and care homes in 1990. For this reason, Table 3 presents a range of estimates of the number of homes needed in 1990 based on the estimated range of persons projected to need this service. As seen, by 1990 between one-half to well over one million board and care homes may be needed to support between 1.6 to 4.8 million persons estimated to need such services--or between 12% and 36% of those estimated to require long-term care in a noninstitutional setting.

Table 3

ALTERNATIVE ESTIMATES OF THE NUMBER OF BOARD AND CARE HOMES AND RESIDENTS: 1990

(000)

Estimated Number of of Residents	Estimated Number of Board and Care Homes, Assuming Alternative Average Number of Residents per Facility		
	3	6	9
4,768	1,589	795	530
3,809	1,270	634	423
2,849	959	475	317
1,627	542	271	181

These estimates suggest that a substantial number of persons could need community-based residential care by 1990. They must, however, be viewed as highly speculative and also as conservative. While the need for these services is growing, the capacity to care for dependent persons at home appears to be experiencing a long-term decline for a number of reasons:

- Those elderly most in need of care are single, divorced or widowed women over 75 and living alone.[15]
- Many of the caregivers are themselves elderly persons who have a higher probability of becoming dependent on others.
- The changing characteristics of the elderly, i.e., the growing number of the oldest old, are changing the need for caregiver skills.
- The increased participation of women in the labor force suggests there will be reduced capacity to care for dependent persons of all ages at home.
- Family size is expected to continue declining, thereby reducing the pool of caregivers.
- Throughout the 1980s, an increasing divorce rate is creating fragmented and redefined families.
- A number of long-distance families are being created as a result of the geographic mobility of the U.S. population.

At the same time, spiraling health care costs and competing uses for health care facilities have made institutional care a less attractive alternative for providing long-term care:

- Medicare limitations on hospital reimbursement for care have accelerated the demand for nursing home beds for short-stay post-hospital recuperation. Nursing home beds are also in short supply in many places because of state limitations on bed construction, designed to reduce Medicaid cost by keeping elderly persons out of institutions. Other state programs (e.g., gatekeeping functions) have the same aim.

- There have been an increased concern with the high cost of care in even smaller institutions (e.g., nursing homes, ICF/MRs), and a concerted effort of policy officials at all levels of government to seek less expensive care alternatives. Board and care is one of the alternatives most often examined.

CONCLUSION

Effective planning to meet the needs of those requiring long-term care requires information on the continuum of services they will need and on the ability of the caregiving system to provide them over the longer term.

ENDNOTES

1.Board and care homes furnish food and shelter to dependent persons unrelated to the operator. The residents normally require some protective supervision or personal assistance with activities of daily living but not professional nursing care except in an emergency.

2.These estimates were obtained from Spenser, Gregory, **Projections of the Population of the U.S. by Sex, Age and Race, 1983 to 2080, Current Population Survey Reports**, Series P-25, No. 952, May 1984. Using mid-range projections, the number of persons 65 and over is projected to increase from 25.5 million persons in 1980 to 31.7 million persons in 1990. In total, 13.7 million persons are projected to be 75 or older by the year 1990.

3.See endnote 1.

4.For example, the Community Mental Health Centers Act (PL 95-622), the Developmental Disabilities Act (PL 95-602), the Older Americans Act, Title XVI of the Social Security Act, the Keys Amendment to PL 94-566, and the Unemployment Compensation Amendment of 1976. The Home and Community Based Care Waivers legislation, passed as part of the Omnibus Reconciliation Act of 1981, is particularly important since it enables Medicaid to pay for services provided to residents of board and care homes rather than forcing them into institutional settings.

5.For information on the vulnerable elderly, extensive reliance was placed on Kenneth G. Manton, Ph.D., and Korbin Liu, Sc.D., **The Future Growth of the Long-Term Care Population: Projections Based on the 1977 National Nursing Home Survey and the 1982 Long-Term Care Survey**, a paper presented at The Third National Leadership Conference on Long-Term Care Issues: "The Future World of Long-Term Care," Washington D.C., March 7-9, 1984, which developed projections of the number of institutionalized and noninstitutionalized disabled elderly 65 and over. Their estimates of the number of institutionalized elderly in 1990 are used in this report. Estimates of the noninstitutionalized elderly population are derived from information in their report on noninstitutionalized persons over 65 who had a limitation in either an activity of daily living or in an instrumental activity of daily living. Estimates of the number of institutionalized and non-institutionalized seriously and persistently mentally ill were provided by Dr. Ronald W. Manderscheid, Alcohol, Drug Abuse and Mental Health Administration, Department of Health and Human Services. Estimates of the number of developmentally disabled were developed from information obtained from an unpublished paper, **Federal Policies Affecting Persons with Developmental Disabilities**, by K. Charlie Lakin, Center for Residential and Community Services, University of Minnesota and covers those with an "active" prevalence of a developmental disability, e.g., persons whose conditions cause severe intellectual or behavioral deficits. A crude estimate of the number of developmentally disabled persons requiring institutionalization was developed by the author of this article. Unpublished tables showing the derivation of all the estimates are available on request.

6.Michele Adler, Suzanne Kitchem and Albert Irion, **Data Book on the Elderly: A Statistical Profile**, Office of the Assistant Secretary for Planning and Evaluation, Department of Health and Human Services, June 1987.

7.Recent survey results have found a lower need for assistance with activities of daily living among noninstitutionalized elderly persons than among nursing home residents. See: Ester Hing, Division of Health Care Statistics, **Use of Nursing Homes by the Elderly: Preliminary Data from the 1985 National Nursing Home Survey**, Advancedata from Vital and Health Statistics of the National Center for Health Statistics, Number 135, May 14, 1986.

8.Persons were considered to have a functional limitation if they had difficulty performing one or more of the following activities: seeing, hearing, speaking, lifting or carrying, walking, using stairs, getting around outside or getting into or out of bed. They were considered to have a severe functional limitation if they were unable to perform one or more of the activities or if they needed the help of another person in order to perform one or more of the activities.

9.Unpublished tabulations available from the author. See: U.S. Department of Commerce, Bureau of the Census, **Disability, Functional Limitation and Health Insurance Coverage: 1984/85**, December 1986, for a detailed description of this data. In addition, information contained in that report showing that 19% of children with a mental or emotional disability only cannot attend or will not attend regular school was used in estimating the number of children at risk of needing community-based residential care. Unpublished information from the National Long-Term Care Survey was used to estimate the number of adults 65 and older living with a related householder other than a son or daughter.

10.The son or daughter of an elderly person 85+ is likely to be in his/her sixties.

11.op.cit, SIPP report.

12.See: Deborah Dawson, Ph.D., and Gerry Hendershot, Ph.D., Division of Health Interview Statistics and John Fulton, Ph.D., Brown University, **Aging in the Eighties: Functional Limitations of Individuals 65 Years and Over**, Advancedata from Vital and Health Statistics of the National Center for Health Statistics, Number 133, June 10, 1987.

13.Vincent Mor, Ph.D., Sylvia Sherwood, Ph.D., and Claire Gutkin, Ph.D., **A National Study of Residential Care for the Aged, The Gerontologist**, Volume 26, Number 4, August 1986.

14.The **National Census of Residential Facilities: FY 1982**, Center for Residential and Community Services, Department of Educational Psychology, University of Minnesota, Minneapolis, Minnesota, September 1984, found that between 1977 and 1982 there was a 41.4% increase in the number of group residences with 1 to 15 residents and an 87% increase in the number of residents of these homes. Group residences opening in 1977 had an average of 13.1 residents, while those opening in 1982 had an average of 6.2 residents. **Board and Care for Elderly and Mentally Disturbed Populations, Final Report, Volume IV: A Review of the Literature**, the Denver Research Institute, Social Systems Research and Evaluation Division, University of Denver, Denver, Colorado, March 1983, presented the findings of several other studies showing that in 1976 the average number of residents in foster care homes for the mentally ill was 1.8 (Murphy, Inglesmann and Techeng-Larouche) and that in the early 1980s a survey of adult foster care homes conducted by the State of Michigan found that 72% of adult foster homes were converted single-family residences and 20% were small-group homes. In addition, a 1983 study of licensed board and care homes in California found that 68% of the homes serving the elderly and 58% serving the mentally retarded have six or fewer beds. (See: **Community Residential Care in California**, report by the Commission on California State Government Organizations and Economy, San Francisco, California, December 1983.) Other studies have found similar results. (See: Robyn Stone, Robert J. Newcomber and Marilyn Saunders, **Descriptive Analysis of Board and Care Policy Trends in the 50 States**, Aging Health Policy Center, University of California, San Francisco, California, September 1982; Claire Gutkin, Clarence Sherwood and Vincent Mor, **Domiciliary Care Programs Across the Nation, Implementing an Option in Long-Term Care**, Hebrew Rehabilitation Center for Aged, Department of Social Gerontological Research, Boston, Massachusetts, March 1982; and **Service Delivery Assessment of Boarding Homes**, Office of the Principal Regional Official, Region III, Washington D.C., July 1979.

15.For a discussion of this and following points, see: Adler, et.al., op.cit.; Robyn Stone, Dr.P.H., Gail Lee Cafferate, Ph.D., and Judith Sangle, M.P.H., **Caregivers of the Frail Elderly: A National Profile**, presented at the 32nd Annual Meeting of the American Society on Aging, San Francisco, California, March 1986 and Sean M. Sweeney, Ph.D., **Family Caregiving: A Synthesis Evaluation, New Areas for Research and Demonstrations and Policy Options**, Office of Human Development Services, Department of Health and Human Services.

Fourth Plenary Session

National Institute on Aging Programs and State Research Needs

DATA FOR AN AGING POPULATION

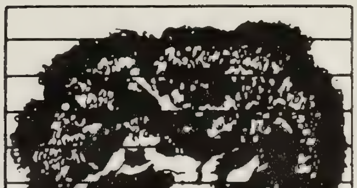
NATIONAL INSTITUTE ON AGING PROGRAMS AND STATE RESEARCH NEEDS

This informal session was chaired by Richard Suzman, Ph.D., from the National Institute on Aging, and covered:

> A description of the National Institute on Aging's biomedical and social research program, including priority initiatives.
>
> Mechanisms and methods of applying for National Institute on Aging research grants.
>
> A discussion with persons working at the State level on their view of important research priorities.

No formal papers were presented at this session.

Appendix



DATA FOR AN AGING POPULATION

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PROGRAM SESSION ORGANIZERS

Ronald Abeles, Ph.D. (U)
Deputy Associate Director
Behavioral Sciences Research
National Institute on Aging
National Institutes of Health
Bethesda, MD 20892

Robert Bilgrad (P)
Special Assistant to the Director
Division of Vital Statistics*

Lester R. Curtin, Ph.D. (E)
Chief, Statistical Methods Staff
Office of Research and Methodology*

Pennifer Erickson (I)
Chief, Clearinghouse on Health Indexes*

Jacob J. Feldman, Ph.D. (1st Plenary)
Associate Director
Office of Analysis and Epidemiology*

George A. Gay (AA)
Chief, Registration Methods Branch
Division of Vital Statistics*

Marjorie S. Greenberg (Z)
Program Analyst, Planning, Evaluation and Legislation Staff
Office of Planning and Extramural Programs*

Tamara Harris, M.D. (1st Plenary,W)
Medical Service Fellow
Office of Analysis and Epidemiology*

Richard J. Havlik, M.D. (F,K,BB)
Special Assistant for Biomedical Applications
Office of Planning and Extramural Programs*

Robert L. Heuser (Z)
Chief, Natality Statistics Branch
Division of Vital Statistics*

Keith L. Hoffman (Y)
Mathematical Statistician
Survey Design Staff
Office of Research and Methodology*

Edward L. Hunter (B)
Planning, Evaluation, and Legislation Staff
Office of Planning and Extramural Programs*

Mary Grace Kovar, Dr. P.H. (S)
Special Assistant for Data Policy and Analysis
Office of Vital and Health Statistics Systems*

Andrea Z. LaCroix, Ph.D. (O)
Epidemiologist, Epidemiology, Demography, and Biometry Program
National Institute on Aging, NIH
Federal Building, Room 612
Bethesda, MD 20892

Jennifer Madans, Ph.D. (U)
Deputy Director, Division of Analysis*

Harry M. Rosenberg, Ph.D. (L)
Chief, Mortality Statistics Branch
Division of Vital Statistics*

Patricia Royston (Y)
Mathematical Statistician
Office of Research and Methodology*

Paula J. Schneider (V)
Chief, Population Division
U.S. Bureau of the Census
Washington, DC 20233

Sandra Surber Smith (C)
Chief, Scientific and Technical Information Branch*

Richard M. Suzman, Ph.D. (E,G,J,Q,R,W)
Behavioral and Social Research
National Institute on Aging
National Institutes of Health
Building 31, Room 4C-32
Bethesda, MD 20892

Cynthia M. Taeuber (H,Q,R,T)
Special Assistant for Selected Populations
Population Division
U.S. Bureau of the Census
Washington, DC 20233

Joan F. Van Nostrand (1st,2nd,3rd Plenary,B,D,J,M)
Deputy Director
Division of Health Care Statistics*

James A. Weed, Ph.D. (N)
Deputy Director
Division of Vital Statistics*

P. Douglas Williams (X)
Chief, State and Academic Research Applications Staff
Office of Planning and Extramural Programs*

Ronald W. Wilson (A)
Director, Division of Epidemiology and Health Promotion
Office of Analysis and Epidemiology*

Martynas Ycas, Ph.D. (D)
Office of Research and Statistics
Social Security Administration
1875 Connecticut Avenue, NW.
Washington, DC 20009

* NATIONAL CENTER FOR HEALTH STATISTICS
3700 East West Highway
Hyattsville, MD 20782

( ) Indicates Session

PROGRAM SESSION CHAIRPERSONS

W. Edward Bacon, Ph.D. (BB)
Director, Division of Health Care Statistics
National Center for Health Statistics
3700 East West Highway
Hyattsville, MD 20782

John E. Brockert (N)
Director, Bureau of Vital Records
Utah Department of Health
P.O. Box 16700
Salt Lake City, UT 84116-0700

J. David Curb, M.D. (L)
Associate Director for Epidemiology,
Demography, and Biometry
National Institute on Aging, NIH
7550 Wisconsin Avenue
Room 612, Federal Building
Bethesda, MD 20892

Pennifer Erickson (I)
Chief, Clearinghouse on Health Indexes
National Center for Health Statistics
3700 East West Highway
Hyattsville, MD 20782

Reynolds Farley, Ph.D. (H)
Professor of Sociology and Research Scientist
Population Studies Center
University of Michigan
1225 South University Avenue
Ann Arbor, MI 48104-2590

Manning Feinleib, M.D., Dr.P.H. (1st,2nd,3rd
Director Plenary,J)
National Center for Health Statistics
3700 East West Highway
Hyattsville, MD 20782

William T. Friedewald, M.D. (P)
Associate Director for Disease Prevention
National Institutes of Health
9000 Rockville Pike
Bethesda, MD 20892

Jack M. Guralnik, M.D., Ph.D. (Z)
Senior Staff Fellow in Epidemiology
National Institute on Aging, NIH
7550 Wisconsin Avenue, Fed. Bldg., Rm. 612
Bethesda, MD 20892

A. Regula Herzog, Ph.D. (Y)
Associate Research Scientist
Survey Research Center and Institute
of Gerontology
University of Michigan
426 Thompson Street
Ann Arbor, MI 48106-1248

Alan B. Humphrey, Ph.D. (X)
Associate Professor
Department of Management Sciences
University of Rhode Island
Kingston, RI 02881

Edward L. Hunter (B-Substitute)
Office of Planning and Extramural Programs
National Center for Health Statistics
3700 East West Highway, Room 2-12
Hyattsville, Maryland 20782

Daniel Kasprzyk, Ph.D. (E)
Mathematical Statistician
Population Division
U.S. Bureau of the Census
Washington, D.C. 20233

Frederick L. King (AA)
State Registrar
Minnesota Department of Health
717 Delaware Street, SE.
Minneapolis, MN 55440

Mary Grace Kovar, Dr.P.H. (S)
Special Assistant for Data Policy and Analysis
Office of Vital and Health Statistics Systems
National Center for Health Statistics
3700 East West Highway
Hyattsville, MD 20782

Andrea Z. LaCroix, Ph.D. (O)
Epidemiologist, Edpidemiology,
Demography, and Biometry Program
National Institute on Aging, NIH
Federal Building, Room 612
7550 Wisconsin Avenue
Bethesda, MD 20892

Larry H. Long, Ph.D. (Q)
Chief, Demographic Analysis Staff
Center for Demographic Studies
U.S. Bureau of the Census
Washington, DC 20233

Jennifer Madans, Ph.D. (U)
Deputy Director, Division of Analysis
National Center for Health Statistics
3700 East West Highway
Hyattsville, MD 20782

J. Michael McGinnis, M.D. (A)
Deputy Assistant Secretary for Health
Department of Health and Human Services
Mary E. Switzer Building, Room 2132
330 C Street, SW.
Washington, DC 20201

Mary A. Moien (K)
Chief, Hospital Care Statistics Branch
Division of Health Care Statistics
National Center for Health Statistics
3700 East West Highway
Hyattsville, MD 20782

George C. Myers, Ph.D. (R-Substitute)
Center for Demographic Studies
Duke University
2117 Campus Drive
Durham, NC 27706

( ) Indicates Session

S. Jay Olshansky, Ph.D. (G)
Environmental Scientist
Argonne National Laboratory
Building 362
9700 South Cass Avenue
Argonne, IL 60439

Virginia Reno (D)
Director, Program Analysis Staff
Office of Research and Statistics
Social Security Administration
1875 Connecticut Avenue, NW., Rm. 323-R
Washington, DC 20009

William J. Scanlon, Ph.D. (F)
Co-Director, Center for Health Policy Studies
2233 Wisconsin Avenue
Washington, DC 20007

Paula J. Schneider (V)
Chief, Population Division
U.S. Bureau of the Census
Washington, DC 20233

Richard M. Suzman, Ph.D. (W,4th Plenary)
Behavioral and Social Research
National Institute on Aging
National Instiutes of Health
Building 31, Room 4C32
Bethesda, Maryland 20892

Cynthia M. Taeuber (T)
Special Assistant for Selected Populations
Population Division
U.S. Bureau of the Census
Washington, DC 20233

Joan F. Van Nostrand (M)
Deputy Director
Division of Health Care Statistics
National Center for Health Statistics
3700 East West Highway
Hyattsville, MD 20782

Linda Washington (C-Substitute)
Scientific and Technical Information Branch
National Center for Health Statistics
3700 East West Highway
Hyattsville, MD 20782

PROGRAM SESSION SPEAKERS

Miriam K. Aronson, Ed.D. (W)
Associate Professor of Neurology and Psychiatry
Albert Einstein College of Medicine
1300 Morris Park Avenue
Bronx, NY 10461

G. Lawrence Atkins (B)
Professional Staff Member
U.S. Senate Special Committee on Aging
SH-404 Hart Senate Office Building
Washington, DC 20510

Ronald E. Aubert (L)
Epidemiologist
Center for Environmental Health
Centers for Disease Control
Atlanta, GA 30333

Douglas Bachtel, Ph.D. (H)
Extension Sociologist/Community Development
School of Agriculture, Univ. of Georgia
Hoke Smith Annex, Room 325
Athens, GA 30602

William H. Barker, M.D. (K)
Associate Professor
Department of Preventive Medicine
University of Rochester Medical Center
601 Elmwood Avenue, Box 644
Rochester, NY 14642

Linda Liska Belgrave, Ph.D. (T)
Co-Investigator, Health and Women's
Retirement Study
Center on Aging and Health
School of Nursing
Case Western Reserve University
Cleveland, OH 44106

Lisa Berkman, Ph.D. (G)
Associate Professor
Department of Epidemiology and Public Health
Yale University School of Medicine
60 College Street
New Haven, CT 06510

Patricia A. Berman (V)
Assistant Chief
Decennial Planning Division
U.S. Bureau of the Census
Washington, DC 20233

Richard Besdine, M.D. (1st Plenary)
Director, Travelers Center on Aging
Travelers Professor of Geriatrics and Gerontology
University of Connecticut Health Center
Farmington, CT 06032

Ronald G. Blankenbaker, M.D. (B)
Vice President for Medical Affairs
St. Vincent Hospital
and Health Care Center
2001 West 86th Street
Indianapolis, IN 46260

Donald J. Brambilla, Ph.D. (S)
Associate Research Scientist
American Institute for Research
1100 Massachusetts Avenue
Cambridge, MA 02138

Jacob A. Brody, M.D. (3rd Plenary)
Dean, School of Public Health
University of Illinois at Chicago
Box 6998
Chicago, IL 60680

Jay S. Buechner, Ph.D. (X)
Chief, Office of Data Evaluation
Rhode Island Department of Health
Cannon Building
75 Davis Street
Providence, RI 02908

Gregory Burke, M.D. (L)
Division of Epidemiology
School of Public Health
University of Minnesota
Stadium Gate 27
Minneapolis, MN 55455

David J. Butler (B)
Deputy Director
Bureau of Management and Strategy, HCFA
1-E-9 Oak Meadows Building
6325 Security Boulevard
Baltimore, MD 21207

Robert N. Butler, M.D. (2nd Plenary)
Brookdale Professor and Chairman
Department of Geriatrics and Adult Development
Mt. Sinai Medical Center
1 Gustave L. Levy Place
New York, NY 10029

Diane Cadell (P)
Project Director
WESTAT
1650 Research Boulevard
Rockville, MD 20850

Neil M. Casey (N)
Director
Division of Health Data Management
Department of Public Health
177 S. Broadway
Akron, OH 44308

Carl J. Caspersen, Ph.D. (A)
Exercise Physiologist/Epidemiologist
Behavioral Epidemiology and Evaluation Branch
Division of Health Education, 3-110
Centers for Disease Control
Atlanta, Georgia 30333

Patricia Colsher, Ph.D. (D)
Research Fellow, Cardiovascular Center
University of Iowa
1945 Steindler Building
Iowa City, IA 52242

( ) Indicates Session

Larry Corder (P-Presented for Manton)
Senior Research Scientist
Duke University
2117 Campus Drive
Durham, NC 27701

John M. Cornman (B)
Executive Director
Gerontological Society of America
1411 K Street, NW.
Washington, DC 20005

J. David Curb, M.D. (AA)
Associate Director for Epidemiology,
Demography, and Biometry
National Institute on Aging, NIH
7550 Wisconsin Avenue
Federal Building, Room 612
Bethesda, MD 20892

A. Michael Davies, M.D., FFCM (J)
Professor and Director, Hebrew Univ., Hadassah
School of Public Health and Community Medicine
P.O. Box 1172
Jerusalem 91010, Israel

Chester Davis (Z)
Health Systems Analyst
810 Vermont Avenue, NW.
Veterans Administration
Washington, DC 20420

Feather A. Davis, Ph.D. (I)
Social Science Research Analyst
Office of Research and Demonstrations, HCFA
Room 2-C-14, Oak Meadows Building
6325 Security Boulevard
Baltimore, MD 21207

J. Edward Dowd (R)
Chief of Epidemiological and
Statistical Methodology Unit
World Health Organization
1211 Geneva 27, Switzerland

Diane Dewar Dunz (T)
Senior Biostatistician
New York Department of Health
Bureau of Biostatistics
Nelson A. Rockfeller Empire State Plaza Tower
Albany, NY 12237

James H. Dwyer, Ph.D. (E)
Associate Professor of Research
Department of Preventive Medicine
University of Southern California
35 North Lake Avenue, Suite 200
Pasadena, CA 91101

Leo F. Estrada, Ph.D. (AA)
Associate Professor
Graduate School of Architecture
and Urban Planning
University of California at Los Angeles
Los Angeles, CA 90024

Denis A. Evans, M.D. (O)
Assistant Professor of Medicine
Harvard Medical School
180 Longwood Avenue
Boston, MA 02115

Manning Feinleib, M.D., Dr.P.H. (1st Plenary)
Director
National Center for Health Statistics
3700 East West Highway
Hyattsville, MD 20782

Daniel J. Foley (S)
Statistician, Epidemiology,
Demography, and Biometry Program
National Institute on Aging, NIH
Federal Building, Room 6-12
7550 Wisconsin Avenue
Bethesda, MD 20892

Linda P. Fried, M.D. (A)
Director, Geriatric Assessment Center
The Johns Hopkins Medical Institutions
600 North Wolfe Street
Carnegie Building, Room 684
Baltimore, MD 21205

E. Greer Gay, Ph.D. (W)
Assistant Professor
Department of Health Administration
School of Public Health
University of South Carolina
Columbia, SC 19108

Dorothy M. Gilford (M)
Study Director
Panel on Statistics for an Aging Population
National Research Council
2101 Constitution Avenue, NW.
Washington, DC 20418

Arnold Goldstein, Ph.D. (V)
Demographic Statistician
Special Populations Staff
Population Division
U.S. Bureau of the Census
Washington, DC 20233

Marian Gornick (K)
Director, Division of Beneficiary Studies
Office of Research and Demonstration, HCFA
Oak Meadows Building, Room 2504
6325 Security Boulevard
Baltimore, MD 21207

Dan J. Grauman (P)
Computer Systems Analyst
Epidemiology and Biostatistics Program
Division of Cancer Etiology
National Cancer Institute
7910 Woodmont Avenue, Room 1201
Bethesda, MD 20892

Ernest M. Gruenberg, M.D., Dr.P.H. (W)
Professor Emeritus
5225 Pooks Hill Road, 222-South
Bethesda, MD 20814

Emily Grundy (J)
Age Concern Institute of Gerontology
King's College London
522 Kings Road, Chelsea Campus
London SW-10 OUA, England

Patricia A. Guhleman (W)
Research Analyst
Center for Health Statistics
Wisconsin Department of Health/Social Services
1 West Wilson, Room 172
Madison, WI 53701-0309

Jack M. Guralnik, M.D., Ph.D. (O)
Senior Staff Fellow in Epidemiology
National Institute on Aging, NIH
7550 Wisconsin Avenue
Federal Building, Room 612
Bethesda, MD 20892

Mary Harahan (F)
Office of the Assistant Secretary
for Planning and Evaluation
Department of Health and Human Services
HHH Building, Room 410E
200 Independence Avenue, SW.
Washington, DC 20201

George E. Hardy, Jr., M.D. (1st Plenary)
Assistant Director/Washington
Centers for Disease Control
Humphrey Building, Room 714-B
200 Independence Avenue, SW.
Washington, DC 20201

Karen S. Harlow, Ph.D. (F)
Director, Institute on Aging/Public Health
Indiana Purdue University
Room 260, Neff Hall
2101 Coliseum Boulevard East
Ft. Wayne, IN 46805

Cynthia Harpine (V-Presented for McNeil)
Statistician, Poverty and Wealth Statistics
Population Division
U.S. Bureau of the Census
Washington, DC 20233

Tamara Harris, M.D.(W)
Medical Service Fellow
Office of Analysis and Epidemiology
National Center for Health Statistics
3700 East West Highway
Hyattsville, MD 20782

Judith D. Kasper, Ph.D. (U)
Assistant Professor
Department of Health Policy and Management
Johns Hopkins School of Hygiene/Public Health
Room 492 - Hampton House
624 North Broadway
Baltimore, MD 21205

John G. Keane, Ph.D. (1st Plenary)
Director
U.S. Bureau of the Census
Washington, DC 20233

Jean E. Kincade, Ph.D. (I)
Assistant Research Professor
The University of North Carolina
at Chapel Hill
Chase Hall 132 A
Chapel Hill, NC 27514

Kevin G. Kinsella (R)
Social Science Analyst
Center for International Research
U.S. Bureau of the Census
Washington, DC 20233

Lorence Tobias Kircher, III, M.D. (L)
Penrose Hospital
POB 7021
Colorado Springs, CO 80933

Anthony Knettel (B)
Professional Staff Member
U.S. House of Representatives
Select Committee on Aging
Room 712, House Office Building, Annex I
300 New Jersey Ave., SE.
Washington, DC 20515

Gary G. Koch, Ph.D. (M)
Professor of Biostatistics
Department of Biostatistics - 318H
School of Public Health
University of North Carolina
Chapel Hill, NC 27514

Mary Grace Kovar, Dr. P.H. (C,W)
Special Assistant for Data
Policy and Analysis
Office of Vital and Health Statistics Systems
National Center for Health Statistics
3700 East West Highway
Hyattsville, MD 20782

Mitchell P. LaPlante, Ph.D. (D)
Assistant Research Sociologist
Institute for Health and Aging, N531-Y
University of California
San Francisco, CA 94143-0646

Anne Lee, Ph.D. (H)
Demographic Consultant
165 Tipperary Road
Athens, GA 30602

Paul E. Leaverton, Ph.D. (U)
Professor and Chairman, Department of
Epidemiology and Biostatistics
College of Public Health
University of South Florida
13301 Bruce C. Downs Boulevard
Tampa, FL 33612

Anthony Lenzer, Ph.D. (Z)
Professor of Public Health
and Human Resources
School of Public Health
University of Hawaii
Honolulu, HI 96822

Korbin Liu, Sc.D. (G)
Senior Research Associate
Health Policy Center
The Urban Institute
2100 M Street, NW.
Washington, DC 20037

Charles F. Longino, Jr., Ph.D. (Q)
Professor
Center for Social Research in Aging
University of Miami
P.O. Box 248092
Coral Gables, FL 33124

David M. Macfadyen, M.D. (J)
Manager, Global Programme on Health
of the Elderly
WHO Euro Regional Office
8 Scherfigsvej
D.K. 2100 Copenhagen, Denmark

Nobuo Maeda, Dr. Medical Science (J)
Head, Section of Social Security
The Institute of Public Health
6-1 Shirokanedai 4 Chome
Minato-ku Tokyo, Japan 108

Kenneth G. Manton, Ph.D. (G,P)
Research Professor of Demographic Studies
Center for Demographic Studies
Duke University
2117 Campus Drive
Durham, NC 27706

Evelyn Mathis (C)
Chief, Long-Term Care Statistics Branch
Division of Health Care Statistics
National Center for Health Statistics
3700 East West Highway
Hyattsville, MD 20782

J. J. McArdle, Ph.D. (U)
Assistant Professor of Quantitative Psychology
Department of Psychology
University of Virginia
Charlottesville, VA 22901

Alma B. McMillan (BB)
Social Science Research Analyst
Office of Research and Demonstration, HCFA
Oak Meadows Building, Room 2C-16
6325 Security Boulevard
Baltimore, MD 21207

David Bryon McMillen, Ph.D. (C)
Statistician
Population Division
U.S. Bureau of the Census
Washington, DC 20233

John McNeil (V)
Chief, Poverty and Wealth Statistics
Population Division
U.S. Bureau of the Census
Washington, DC 20233

David Mechanic, Ph.D. (1st Plenary)
Rene Dubos Professor of Behavioral Science and
Director, Institute of Health, Health Care
Policy, and Aging Research
Institute for Health Policy
Rutgers University
30 College Avenue
New Brunswick, NJ 08903

Baruch Modan, M.D. (J)
Chaim Sheba Medical Center
Tel-Aviv University
Sacler School of Medicine
Tel-Hashomer 52621, Israel

Marilyn Moon, Ph.D. (B)
Director, Public Policy Institute
American Association of Retired Persons
1909 K Street, NW.
Washington, DC 20049

Jana M. Mossey, Ph.D. (S)
Associate Professor, Department of
Community and Preventive Medicine
Eastern Pennsylvania Psychiatric Institute
Medical College of Pennsylvania
2900 Henry Avenue
Philadelphia, PA 19129

Douglas R. Murray (X,N-Presented for Nashold)
Section Chief
Service Data Section
Wisconsin Center for Health Statistics
P.O. Box 309
Madison, WI 53701

Ross M. Mullner, Ph.D. (K)
10301 South Kostner
Oaklawn, IL 60453

Patricia Nametz (Z)
Public Health Educator
Wisconsin Center for Health Statistics
1 West Wilson Street
P.O. Box 309
Madison, WI 53701-0309

Raymond D. Nashold, Ph.D. (N)
Director
Center for Health Statistics
Wisconsin Division of Health
1 West Wilson Street, P.O. Box 309
Madison, WI 53701

Aulikki Nissinen, M.D. (J)
Division of Non-Communicable Disease
World Health Organization
1211 Geneva 27, Switzerland

Leonard Norry, Ph.D. (V-Presented for Berman)
Assistant Chief, Housing Division
U.S. Bureau of the Census
Washington, DC 20233

Robert A. Pollard, Jr. (A-Presented for Caspersen)
Mathematical Statistician, Center for
Health Promotion and Education
Centers for Disease Control, MS A14
1600 Clifton Road, NE.
Atlanta, Georgia 30333

Patricia W. Potrzebowski, Ph.D. (AA)
Director, Division of Health
Statistics and Research
Pennsylvania Department of Health
P.O. Box 90
Harrisburg, PA 17108

W. Michael Reid, Ph.D. (X)
Director, Division of Planning
Bureau of Medical Services
Office of Health Planning Development
151 Capitol Street, Station No. 11
Augusta, ME 04333

Dorothy P. Rice, Sc.D. (Hon.) (M)
Professor
Institute for Health and Aging
School of Nursing
University of California
Box 0612 - N631
San Francisco, CA 94143

Willard L. Rodgers, Ph.D. (Y)
Associate Research Scientist
Institute for Social Research
University of Michigan
P. O. Box 1248
Ann Arbor, MI 48106

Andrei Rogers, Ph.D. (Q)
Director, Population Program
Institute of Behavioral Sciences
Campus Box 484
University of Colorado
Boulder, CO 80309

Marilyn J. Rosenstein (F)
Chief, Patient Survey Program
Survey and Reports Branch, NIMH
Parklawn Building, Room 18C-07
5600 Fishers Lane
Rockville, MD 20857

Anita Roth (I)
10319 Gary Road
Potomac, MD 20854

Richard B. Rothenberg, M.D. (N)
Assistant Director for Science
Division of Chronic Disease Control
Centers for Disease Control
Atlanta, GA 30333

William J. Serow, Ph.D. (O)
Professor of Economics
Population Center
Florida State University
653 Bellamy Building
Tallahassee, FL 32306-4063

Evegnei Shigan, M.D. (J)
Director
Division of Non-Communicable Diseases
World Health Organization
1211 Geneva 27, Switzerland

Burton H. Singer, Ph.D. (G)
Professor, Public Health (Biostatistics)
Department of Epidemiology and Public Health
Yale University School of Medicine
60 College Street
New Haven, CT 06510

Nancy Smith (R)
Professional Staff
Select Committee on Aging
U.S. House of Representatives
Room 721, HOB, Annex #1
Washington, DC 20515

Anne R. Somers, D.Sc. (Hon.) (3rd Plenary)
Adjunct Professor, University of Medicine
and Dentistry of New Jersey
Robert Wood Johnson Medical School
31 Scott Lane
Princeton, NJ 08540

Gregory Spencer, Ph.D. (O)
Demographer
Population Division
U.S. Bureau of the Census
Washington, DC 20233

Richard M. Suzman, Ph.D. (C)
Behavioral and Social Research
National Institute on Aging
Building 31, Room 4C32
National Institutes of Health
Bethesda, MD 20892

Cynthia M. Taeuber (H)
Special Assistant for Selected Populations
Population Division
U.S. Bureau of the Census
Washington, DC 20233

Sharon L. Tennstedt, Ph.D. (Y)
Senior Research Scientist
New England Research Institute
42 Pleasant Street
Watertown, MA 02172

H. Dennis Tolley, Ph.D. (E)
Associate Professor
Department of Statistics
Brigham Young University
Provo, UT 84602

Joan Turek-Brezina, Ph.D. (BB)
Director, Division of Technical Support
Office of the Assistant Secretary
for Planning and Evaluation, DHHS
Hubert H. Humphrey Building, Room 438F
200 Independence Avenue, SW.
Washington, DC 20201

Robert B. Wallace, M.D. (Y)
Professor and Head
Department of Preventive Medicine
2800 SB
University of Iowa
Iowa City, IA 52242

Philip G. Weiler, M.D. (A)
Professor and Director
Center for Aging and Health
School of Medicine
Department of Community Health, TB168
University of California
Davis, CA 95616

Joshua M. Wiener, Ph.D. (2nd Plenary)
Senior Fellow
The Brookings Institution
1775 Massachusetts Avenue, NW.
Washington, DC 20036

David R. Williams, Ph.D. (T)
Assistant Professor
Department of Sociology
Yale University
P.O. Box 1965 Yale Station
New Haven, CT 06520-1965

T. Franklin Williams, M.D. (1st Plenary)
Director
National Institute on Aging
National Institutes of Health
Building 31, Room 2C02
Bethesda, MD 20892

Robert E. Windom, M.D. (1st Plenary)
Assistant Secretary for Health
Department of Health and Human Services
200 Independence Avenue, SW.
Washington, DC 20201

Michael J. Witkin (BB)
Chief, Inventory Program
Survey and Reports Branch, NIMH
Parklawn Building, Room 18C-07
5600 Fishers Lane
Rockville, MD 20857

Martynas Ycas, Ph.D. (D)
Office of Research and Statistics
Social Security Administration
1875 Connecticut Avenue, NW., Rm. 321-P
Washington, DC 20009

Scott Zeger, Ph.D. (E)
Assistant Professor
Department of Biostatistics
Johns Hopkins University
615 N. Wolfe Street
Baltimore, MD 21205

EXHIBITORS

Bureau of Labor Statistics
Health Care Financing Administration
Indian Health Service
National Archives of Computerized Data on Aging
National Center for Health Services Research
National Center for Health Statistics
National Death Index, NCHS
National Eye Institute
National Institute on Aging
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Public Health Reports
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